The State Plan for Arthritis Action in South Carolina

Acknowledgements

This report is a collaborative effort of the South Carolina Arthritis Prevention and Control Program (SCAPCP-- hereinafter called the SC Arthritis Program), the Arthritis Foundation of the Carolinas, and other partners, many of whom are represented on the SC Arthritis Steering Committee. The SC Arthritis Program is a cooperative agreement between the Women's Health Program, Bureau of Community Health, and the Bureau of Home Health and Long Term Care, South Carolina Department Of Health and Environmental Control.

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Executive Summary

According to the Centers for Disease Control and Prevention (CDC), nationally, there are 43 million people with arthritis, costing the country nearly $65 billion annually. Arthritis is second only to heart disease as a cause of work disability. The impact of arthritis in South Carolina is significant, a fact that is increasingly verified by the arthritis surveillance made possible by the 1999 CDC establishment grant funding the SC Arthritis Program. (See "Impact of Arthritis in South Carolina" and "Epidemiology and Research" sections in this report.) Through this first-time funding, South Carolina was able to join with the Arthritis Foundation efforts to design a public health response to some of the most serious chronic, disabling conditions that affect its people: arthritis and other rheumatic conditions.

The State Plan for Arthritis Action in South Carolina, 2001-2005, was developed under the guidance of the SC Arthritis Steering Committee to assess where we stand with arthritis and other rheumatic conditions in this state and to guide us to where we aim to be by year 2005. The SC Arthritis Steering Committee, which joins together representatives from the Arthritis Foundation, hospitals, private practice, state agencies, research centers, universities, and volunteer organizations, is an advisory group to the SC Department of Health and Environmental Control (DHEC). The partnership represented by the SC Arthritis Steering Committee and DHEC is the first organized effort to develop a population-based response within the state's public health agency.

Documented in this first five-year, public health plan for arthritis in South Carolina are some of the difficulties people with arthritis (PWA's) face in obtaining care in the state. These include accessing medical care, affording prescription medications, overcoming transportation barriers, and locating reliable and up-to-date information about arthritis, especially in underserved areas of the state. Plans are described for developing and expanding services to persons with arthritis and their caregivers in the state. Listed are partnerships developed with agencies whose goals and objectives are to care for persons with arthritis in South Carolina.

Public attitudes and lack of knowledge about arthritis may contribute to many not seeking early diagnosis and treatment for arthritis in the state. Strategies for communicating the "arthritis message" are proposed in this report. Increasing public awareness about the impact of arthritis and the importance of prevention, early diagnosis, appropriate management and effective intervention will be the focus of these strategies.

A listing of many agencies and organizations that provide services to PWA's is provided. While this is not an all-inclusive list, it provides information on public service providers, local hospitals, fitness centers, and services provided by the Arthritis Foundation of the Carolinas. Arthritis treatment and care services are documented with some success, indicating also where service gaps exist. Other facets of treatment and care are addressed in the discussions of the use of complementary and alternative medicine (CAM) and the role of nutrition for persons with osteoarthritis and rheumatoid arthritis.

In these first two years of the arthritis establishment program in South Carolina, it has become evident that arthritis programs, services, treatment and care are available, but considerably limited for the amount of need. They are offered in key regions of the state, but far less so in the rural areas where the need is greater, based on SC BRFSS prevalence findings. Many are listed with the Arthritis Foundation of the Carolinas information, but many are not linked to any centralized information and referral source. These findings, and others, have clear implications for the work that needs to be done in

the next five years and beyond in South Carolina. *The State Plan for Arthritis Action in South Carolina, 2001-2005*, is the blueprint for how the SC Arthritis Prevention and Control Program and the SC Arthritis Steering Committee envision carrying this out.

Contents

V. Access To Care

A. Medical Care*
B. Transportation
C. Cost Of Medicines
D. Financial
E. Access To Services
F. Access To Information

*Under each topic, "Where We Want to Go" is addressed

VI. Other Considerations for Arthritis Treatment and Care

A. Complementary and Alternative Medicine Use in South Carolina
B. Nutrition and Arthritis

VII. Priorities and Objectives: How Will We Get There?

A. Five Year Plan Objectives
B. Timeline

Where We Are in South Carolina

I. Background

A. Arthritis Defined

According to the National Arthritis Action Plan (NAAP)* developed by the Centers for Disease Control and Prevention (CDC) and the national Arthritis Foundation, arthritis and other rheumatic conditions** are among the most common chronic conditions and the leading cause of disability in the United States. Arthritis is mistakenly viewed by many as mostly a nuisance condition --little aches and pains that accompany old age. In fact, arthritis can affect people of all ages, including children, and can cause very serious conditions and complications.

These conditions frequently lead to limitations in work, recreation, and usual activities, including basic self-care. Some types of arthritis can result in life-threatening complications. The term "arthritis," as used here, encompasses more than 100 diseases and conditions affecting joints, the surrounding tissues, and other connective tissues. These diseases and conditions include osteoarthritis (OA), rheumatoid arthritis (RA), gout, fibromyalgia, bursitis, rheumatic fever, lupus, and Lyme disease. Three of the most common forms of arthritis are osteoarthritis, rheumatoid arthritis, and fibromyalgia.

The SC Arthritis Program will respond to general public requests for information, resources, and referral on arthritis and other rheumatic conditions and will generally cover them through public information and education efforts. However, for the purposes of this five-year state plan, osteoporosis, RA, and fibromyalgia are the three conditions that will be discussed and targeted for action.

- **Osteoarthritis (OA)**, or "degenerative joint disease," causes the cartilage and bones in the body to degenerate. It most often affects the hip, knee, foot, and hand, but can affect other joints as well. Degeneration of joint cartilage and changes in underlying bone and supporting tissues lead to pain, stiffness, movement problems, and activity limitations. About one half of those 65 and older have this disease. Nationally, 15.3 million women have OA. In South Carolina, women, African Americans, Hispanics, and people of low education are disproportionately affected by osteoarthritis or chronic joint symptoms.

- **Rheumatoid arthritis (RA)** is characterized by chronic inflammation of the joint lining. Symptoms include pain, stiffness, and swelling of multiple joints. The inflammation may extend to other joint tissues and cause bone and cartilage erosion, joint deformities, movement problems, and activity limitations. Rheumatoid arthritis can also affect connective tissue and blood vessels throughout the body, triggering inflammation in a variety of organs, including the lungs and heart, and increasing a person's risk of dying of respiratory and infectious diseases. Nationally, 1.5 million women have RA.

- **Fibromyalgia** is a pain syndrome, disproportionately affecting more women than men, involving muscle and muscle attachment areas. Common symptoms include widespread pain throughout the muscles of the body, sleep disorders, fatigue,

headaches, and irritable bowel syndrome. Very little is known or understood about the etiology of this disease. Diagnosis is difficult, and once made, the condition is very hard to treat. Anecdotal reports show that for patients who can afford it, they have often sought complementary medicine treatments, such as massage therapy and acupuncture, for relief from their pain and disability. Nationally, fibromyalgia affects 3.7 million people, mostly women.

** Hereafter, any reference to "arthritis" refers to the 100 conditions classified by the Arthritis Foundation as "arthritis and other rheumatic conditions."

*For more information on the NAAP please contact
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B. The Impact of Arthritis in South Carolina

Prevalence

The prevalence data on arthritis for South Carolina are based on the Behavioral Risk Factor Surveillance Survey (BRFSS). The BRFSS is a random digit-dialed telephone survey of adults, age 18 years and older developed by the Centers for Disease Control and Prevention. According to the 2000 SC BRFSS, approximately 906,003 (32%) out of 2,831,079 non-institutionalized adults in South Carolina have arthritis. Persons with arthritis were defined as those having either chronic joint symptoms (CJS) or doctor-diagnosed arthritis, which is the CDC-recommended case definition for arthritis. Twenty-five percent of South Carolina adults reported doctor-diagnosed arthritis and 20% reported CJS. As seen in Table # 1, this prevalence estimate was higher for women, increased with age, and decreased with higher education levels.

Table # 1 Prevalence rate of arthritis by selected characteristics - SC BRFSS, 2000

Characteristic	%
Sex	
Female	36.9
Male	26.7
Age (years)	
18-44	17.6
45-64	43.1
≥ 65	59.5
Education (years)	
<8	54.6
9-11	42.9
12 or equivalent	33.4
13-15	27.3
16+	27.3
Race/Ethnicity	
White, non-Hispanic	33.7
Black, non-Hispanic	27.6
Hispanic	34.5
Other	22.5

Economic Indicators – Cost of Arthritis Care

South Carolina Hospital Discharge and Emergency Room data were used to measure the cost of arthritis care on the health-care system. Arthritis and other rheumatic conditions were defined using the National Arthritis Data Workgroup definition *. Persons with a primary diagnosis of arthritis and other rheumatic conditions accounted for 1.9% (9,297) of all hospital discharges and 2.8% (35,394) of all emergency room visits. Of these hospital discharges among persons with arthritis, women accounted for 61.7% and persons aged 65 years and older for 49.4%. Of these emergency room visits among persons with arthritis, women accounted for 56.7% and persons less than 65 years of age for 83.2% (Table #2).

Persons with arthritis and other rheumatic conditions accounted for 1.8% (approximately 43,000) of days of hospital care, with an average length of stay similar to the average for all patients (approximately 5 days). In 1999, total charges for persons with arthritis and other rheumatic conditions were over 164 million dollars for hospital visits and over 11 million dollars for emergency room visits.

Table # 2 **Number and percentage distribution of hospital discharges and emergency room visits for all conditions and for primary diagnosis of arthritis and other rheumatic conditions, by patient age and sex – SC Hospital Discharge and SC Emergency Room Data, 1999**

	Hospital		Emergency Department	
Characteristic	**Number of discharges**	**% of all arthritis discharges**	**Number of visits**	**% of all arthritis discharges**
All conditions	486,373	-----	1,286,065	-----
Arthritis and other rheumatic conditions	9,297	100.0	35,394	100.0
Age (yrs.)				
<15	202	2.2	1,903	5.4
15-44	1,190	12.8	17,854	50.5
45-64	3,307	35.6	9,707	27.4
≥65	4,580	49.4	5,891	16.7
Sex				
Male	3,565	38.3	15,319	43.3
Female	5,732	61.7	20,074	56.7

(Continuation from Table 2)

* International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) codes 95.6, 95.7, 98.5, 99.3, 136.1, 274, 277.2, 287.0, 344.6, 353.0, 354.0, 355.5, 357.1, 390, 391, 437.4, 443.0, 446, 447.6, 696.0, 710-716, 719.0, 719.2-719.9, 720-721, 725-727, 728.0-729.3, 728.6-728.9, 729.0-729.1, and 729.4.

Quality of Life

Four self-reported general health-related quality of life questions from the BRFSS cover overall health and recent physical health, mental health, and activity limitation. Data from the 2000 SC BRFSS were analyzed to assess the health-related quality of life for persons with arthritis in South Carolina. When asked about their general health status, fewer people with arthritis reported at least good health. Seventy percent of persons with arthritis reported at least good health compared to 93% of persons without arthritis.

Persons with arthritis reported a higher number of days of poor mental health, poor physical health, and limitation in usual activities (Figure # 1). Additionally, persons with arthritis reported five fewer healthy days (in the last 30 days) than persons without arthritis. Persons with arthritis reported a higher number of days of depression and anxiety than persons without arthritis. Additionally, persons with arthritis reported six more days (in the last 30 days) of pain and five fewer days (in the last 30 days) when they felt very healthy and full of energy than persons without arthritis (Figure # 2).

Figure # 1 **Average Number of Unhealthy Days and Days of Poor Mental Health, Poor Physical Health, and Usual Activity Limitation (in past 30 days) – SCBRFSS 2000**

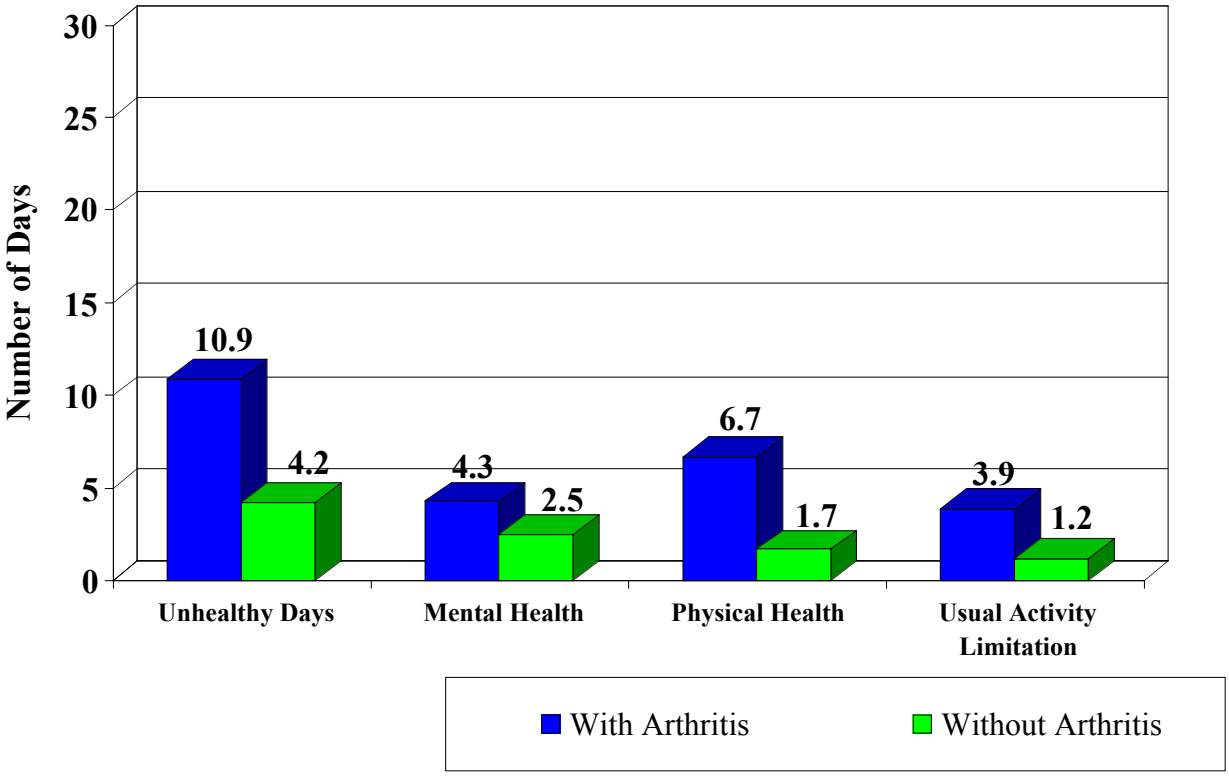
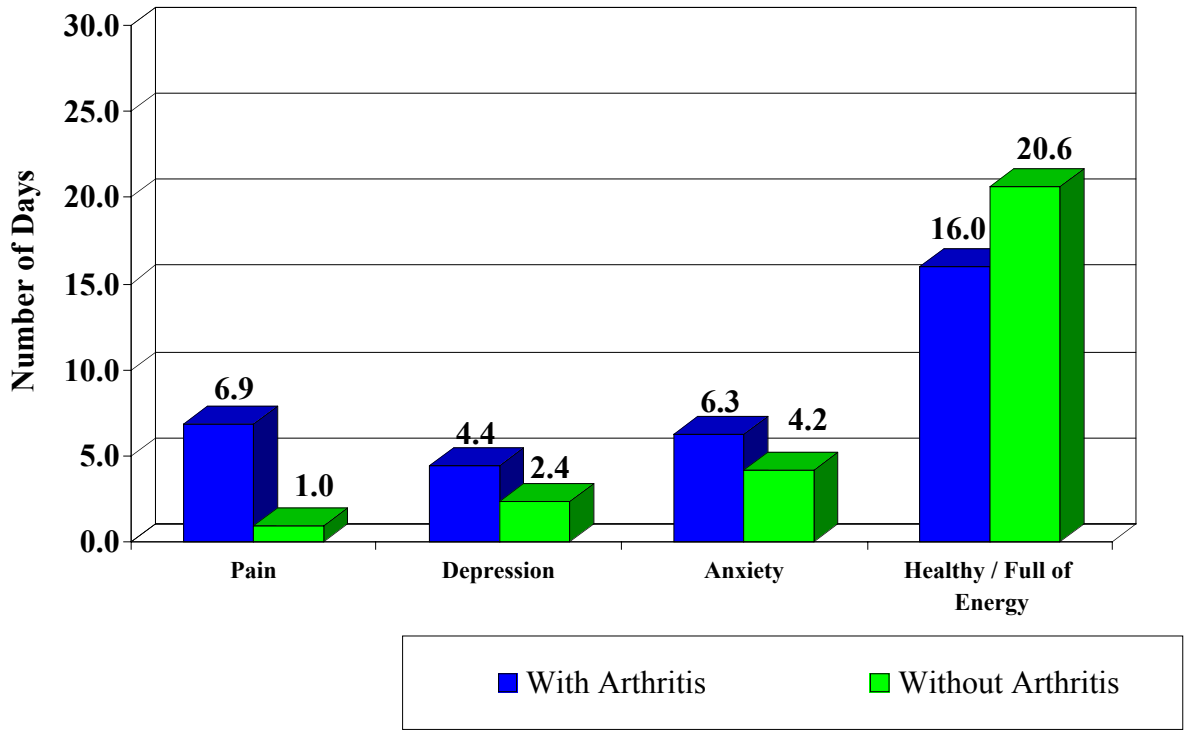


Figure # 2 **Average Number of Days with Pain, Depression, Anxiety, and Healthy/Full of Energy (in past 30 days) - SC BRFSS, 2000**



Functional Limitation

For three years, the SC DHEC In-Home Prevention Project has served well seniors age 65 and older. Based on preliminary analysis of 326 clients, 64% reported having arthritis. Seventeen percent of clients reported having at least any one of five activities of daily living (ADLs) limitations, including dressing, toileting, ambulating, feeding, and hygiene. This is consistent with national data that shows that among people with an ADL limitation, 69% reported having arthritis. Among people without ADL limitation, 63% reported having arthritis.

According to the 2000 SC BRFSS, approximately 401,004 (14.1 percent) out of 2,840,116 non-institutionalized adults in South Carolina have some degree of disability due to an impairment or health problem. When asked for the cause or source of the major impairment for the disability, a wide variety of conditions were selected by South Carolina adults as seen in Table # 3. The most common reason was back or neck problems, which accounted for 20.9 percent of disability. Arthritis was listed as the second most common reason for disability, accounting for 13.9 percent of disability.

Table # 3 Major Impairment or Health Problem Reported by Respondents with Disability - SC BRFSS, 2000

Major Cause	%
Back or Neck Problem	20.9
Arthritis/Rheumatism	13.9
Fractures, Bone/Joint Injury	9.3
Lung/Breathing Problem	7.9
Walking Problem	6.5
Heart Problem	4.2
Depression/Anxiety/Emotional Problem	3.0
Diabetes	2.2
Eye/Vision Problem	1.6
Cancer	1.2
Hearing Problem	1.1
Stroke Problem	0.8
Hypertension/High Blood Pressure	0.1
Other Impairment/Problem	27.4

According to the 2000 SC BRFSS, 22% of participants reported activity limitation due to CJS. Persons with CJS were defined as those having pain, aching, stiffness, or swelling in or around a joint in the past year, with these symptoms present on most days for at least one month. As seen in Table # 4, this prevalence estimate was higher for women, increased with age, and decreased with higher education levels.

Table # 4 **Prevalence rate of activity limitation attributable to chronic joint symptoms by selected characteristics - SC BRFSS, 2000**

Characteristic	%
Sex	
Female	24.8
Male	17.8
Age (years)	
18-44	14.8
45-64	25.5
≥ 65	28.4
Education (years)	
<8	30.0
9-11	30.7
12 or equivalent	24.4
13-15	19.3
16+	14.9
Race/Ethnicity	
White, non-Hispanic	22.2
Black, non-Hispanic	18.5
Hispanic	43.0
Other	13.9

Psycho-Social, Psychological and Medical Complications

Fear, depression, anger, and anxiety are common emotional responses to coping with chronic disease. According to the Arthritis Foundation (1997), emotional and physical losses associated with arthritis are significant, deeply affecting a person's identity and self-esteem. Social losses may include loss of a job, hobby, sports, relationships, and ability to plan ahead. The physical impact includes the loss of energy and mobility, freedom of choice for activities, being pain free, and the challenge of managing the illness on a frequent or daily basis.

According to Engleman, E.P. & Silverman, M. (1979), some forms of arthritis attack joints and the tendons and muscles associated with joints. Some strike not only the joints, but such organs as the kidneys, lungs, skin, eyes, and blood vessels. Despite these complications, the situation is not as bleak as it may appear. Some forms of arthritis whose complications once led to death can now be effectively controlled with drugs.

Of the three most frequently occurring arthritic conditions, osteoarthritis (OA), rheumatoid arthritis (RA), and fibromyalgia, RA and fibromyalgia usually have the greatest psycho-social, psychological, and medical impact. While osteoarthritis affects far and away the majority of people, the severe suffering caused by the other two merits a public health response as well.

Osteoarthritis

Osteoarthritis is, by far, the most common joint disorder both in the United States and throughout the world. Radiographic and/or pathologic changes of osteoarthritis are present in a majority of persons over age 65, and many of those with pathologic evidence of disease have pain or stiffness in affected joints. Symptoms are common in the hands, knees, and hips, and symptomatic osteoarthritis may partly account for the high prevalence of back and neck pain (Felson, 1993).

Unfortunately, osteoarthritis is not easily treated. Recent studies suggest that the medications most often used to treat osteoarthritis, nonsteroidal anti-inflammatory drugs and aspirin, are frequently ineffective, and that some in this class of drugs may have deleterious effects on cartilage metabolism. Although surgical treatment of affected joints, including the knee and the hip, offers great relief to selected patients, society's solution to the disability burden of osteoarthritis lies only partly in surgery, which is expensive and generally reserved for those in a restricted age range who are most severely affected. Additionally, some commonly affected joints, such as distal interphalangeal (DIP), are not successfully treated by surgery (Felson, 1993).

Rheumatoid Arthritis (RA)

Rheumatoid arthritis is a chronic disabling condition that affects 1% of US adults. It causes substantial morbidity and is associated with a 5- to 15-year reduction in life expectancy. Early death stems not from the arthritis per se, but rather from co-morbid diseases that commonly affect the general population. Several factors may contribute to these premature deaths. First, patho-physiologic features of RA may accelerate the course of other diseases. Next, medications used to treat RA may cause or exacerbate other diseases. Finally, patients with RA may not receive adequate treatment for co-morbid diseases, perhaps because the attention of patients and/or physicians is focused mainly on the arthritis (MacLean et al., 2000).

Clients who have had RA should be assessed for changes in functional ability, deformities, and tolerance of treatment. It is important to continue to assess both their compliance with therapy and their continued ability to cope with this disease and all of its changes. Physical assessment includes inspecting all joints for signs of inflammation, deformity, or limitation of normal movement. Assessment of the whole client is required, not just the joints, because arthritis is a systemic disease. Organs possibly affected include the heart, blood vessels, eyes, and peripheral nerves (Black, Matassarin-Jacobs, 1993).

According to Minuchin, et al. (1978), it appears to be a psycho-social "burden" for many persons with rheumatoid arthritis to ask for assistance because of not wanting to appear dependent or co-dependent or to overtax the good will of family or friends. For those with vulnerable joints, stressing them with heavy or physically complicated tasks without assistance adds days of pain and loss of other kinds of independent movement.

In *A Need for Knowledge* (**The Lexington Chronicle**, October 19, 2000), Mildred Porter, a resident of South Carolina diagnosed with RA in 1997, described the challenges of living with RA:

> I now know how hard it is for a handicapped or infirm person to go to church or go grocery shopping or even to get dressed. I had to take a really deep breath and count to three before I would let anyone see me in a wheel chair or using my walker. There were times when I thought I could not stand it anymore. I now have my RA pretty much under control with the help of my medication. I can walk unassisted again, drive my car, dress alone and do my housework. I can't ride my horse or take my trip to Sante Fe, but I have not given up on them either.

Again, according to Minuchin et al. (1978), to be able to participate and do typical tasks and activities of daily life (including activities in and outside the home with family, friends, and colleagues), the person with RA has to plan far ahead. Conserving one's energy, perhaps not engaging in some daily activities in order to "have energy" and being relatively pain free to be part of family and social functions is important. Protectiveness from threats of physical injury to affected joints modifies or curtails some of life's greatest pleasures. The constant measuring of what one must "give up" in order to continue to be active is ever present in the mind.

Fibromyalgia

Fibromyalgia can also be very hard to cope with on a daily basis. Fibromyalgia is an arthritis-related condition, but unlike arthritis, does not damage joints. Fibromyalgia is a disorder that is characterized by pain in muscles and their attachments to bones. Fibromyalgia is the second most common disorder seen by rheumatologists. According to unpublished data from the National Arthritis Data workgroup, some 3.7 million Americans have fibromyalgia. We do not know the specific number of people in South Carolina diagnosed with fibromyalgia. We do know that services in the state for this condition are limited.

In interviews conducted for this report, members of a Columbia-based Fibromyalgia Support Group and Arthritis Steering Committee members shared the following experiences:

One recalled being referred to as a hypochondriac and being told by a medical profesional that, "Your time is up because I don't have the time to listen to any more complaints today." Another person told how she was discharged from the care of her family physician because she was taking up too much of the doctor's time. Another was told that fibromyalgia does not exist, that "it was just in her head."

A nurse with the disorder stated her belief that fibromyalgia is a very misunderstood disease. She described the many techniques she used to cope with her condition, including enjoying humor, reading encouraging books, and listening to music and inspirational tapes. "My faith has kept me strong," she concluded, "and I continue to hope for a cure for the disease."

Psycho-Social, Psychological, and Medical Strategies: Where We Want to Go

For the most part, the strategies in Chapter III, Communication Education and Prevention, address this area of concern. However, below are some strategies specific to psycho-social, psychological and medical complications of arthritis. They include:

- Educate the public and arthritis health care professionals about the psychological and social impact of arthritis and rheumatoid conditions
- Educate primary health care professionals about therapies and services to supplement medical care, such as individual and family counseling, support groups and encourage appropriate referrals to psychologists, social workers, counselors, occupational and or recreational therapists and others and
- Increase awareness of the general public and health care providers of community resources available to enhance the quality of life for persons with arthritis and arthritis-related conditions.

C. Developing the SC Arthritis Plan

The South Carolina Department of Health and Environmental Control (DHEC) received an "establishment" grant through a cooperative agreement with the Centers for Disease Control and Prevention (CDC) in October 1999 to address the burden of arthritis in South Carolina. The DHEC Bureau Of Community Health Women's Health Program and the Bureau of Home Health and Long Term Care developed a formal agreement to work together to develop the SC Arthritis Prevention and Control Program (SCAPCP), referred to as the SC Arthritis Program. As described in the grant, the goals of the SC Arthritis Program are:

- to establish a state arthritis surveillance system
- to increase public awareness of the seriousness of arthritis
- to address gaps in services and barriers to service
- to lay the foundation for a statewide public health infrastructure addressing arthritis, and
- to write a state arthritis plan

To address the task of developing the *State Plan for Arthritis Action in South Carolina, 2001-2005*, the SC Arthritis Steering Committee met for the first time July 5, 2000. Using the outline from the National Arthritis Action Plan (NAAP) as a guide, members began immediately to develop a framework for writing the state plan. The Arthritis Steering Committee convened again in August and October 2000, January and March 2001. At the August meeting, the Committee documented gaps and barriers to services and care in the state and approved an outline for documenting the burden of arthritis in the state. In October, the committee developed solutions for remedying the gaps and barriers described earlier.

By January, Committee members had divided into sub-groups and agreed to meet other times, in addition to meeting with the Steering Committee. Members agreed to draft "assigned" sections of the plan. Much of the information was combined by mid-January. Major objectives were identified and agreed upon by March 2001. The text was reviewed by the Steering Committee several times and changes and adjustments to the format were discussed and adopted before staff wrote the final draft.

Upon completing the arthritis plan April 30, 2001, the plan will be published and distributed to Arthritis Program partners May-June 2001 and following. Some of the organizations targeted for distribution will include organizations which Steering Committee members represent, as well as other DHEC staff, other partners cited in the Arthritis Partnership Network, the programs and agencies listed in this document for arthritis services, and selected members of the SC General Assembly. State Plan fact sheets for consumer groups, local organizations, health care providers, faith-based institutions, and other community outlets will be discussed at future Steering Committee meetings. Topics will be decided upon and prioritized for development.

D. Development of SC Arthritis Steering Committee

The South Carolina Arthritis Steering Committee was created to advise the DHEC Arthritis Program on the development of and distribution of the South Carolina Arthritis Plan. Between May and July 2000, arthritis experts from around the state were recruited to participate on the Steering Committee. Recruitment is an ongoing process as new experts are referred or found. The Steering Committee also will provide the core group for developing the SC Arthritis Coalition in the next several years.

The SC Arthritis Steering Committee was established initially with 22 members and met for the first time in July 2000. Membership has expanded to 33 members and is comprised of nurses, counselors, occupational therapists, a wellness and fitness coordinator, rheumatologists, a pharmacist, researchers, PWA's, and arthritis and fibromyalgia support group members. It is also comprised of representatives from local hospitals, a health insurance provider, the community aging network, academia and several board members of the Arthritis Foundation of the Carolinas. (Committee members are listed in Appendix I.)

DHEC staff members of the Steering Committee are Melody Crocker, Arthritis Coordinator; Julie Lumpkin, P.I. and Women's Health Manager, and Natalie Scruggs, Epidemiologist. Other support is provided by members of the DHEC Arthritis Coordinating Committee, including Cora Plass, Co-PI and Director of Community and Home Based Services; Ted Hewitt, Public Information Director for In-Home Prevention Services for Seniors; Kathy Talbot, Director, In Home Prevention Services for Seniors; and Manxia Wu, Director, SCBRFSS.

As described above, the SC Arthritis Steering Committee has met five times in nine months to orient themselves to the committee's primary purpose and to begin to develop the South Carolina Arthritis Plan. Recognizing that complementary and alternative medicine was a subject on which members desired more information, presenters to the Committee (several of whom are committee members) have provided information on complementary medicine, including massage therapy, acupuncture, and chiropractic care.

E. Coalition Development: Where We Want to Go

Development and organization of a coalition can facilitate realization of state-based strategies for arthritis, using a broader base of volunteer, professional, and institutional support. South Carolina's vision is to continue providing strong leadership through a team of committed partners based within the DHEC Arthritis Program and a SC Arthritis Coalition. Given the resources needed to develop a statewide coalition, steps

toward that goal will be taken through seeking alliance with the SC Osteoporosis Coalition.

It is envisioned that the SC Arthritis Steering Committee will link with the Osteoporosis Coalition to form a task force or special interest committee to learn coalition development through the Osteoporosis model and to create a long-term alliance. Public education and advocacy projects can be co-coordinated and a strong membership better assured. As the Arthritis Coalition evolves, its mission will be to address the following needs in collaboration with DHEC:

- Identify resources and gaps in services
- Develop public and provider education to increase awareness that arthritis is a condition that can be treated and prevented in some cases
- Advocate for systems change, such as prescription drug reform and an improved, coordinated public transportation system to reach rural populations and improve access to services
- Provide support for research on complementary and alternative medicine
- Promote self-help and self-advocacy to increase involvement in health care decisions and to improve response to medical conditions.
- Improve access to information on arthritis
- Improve access to primary practitioners and rheumatologists
- Provide continuing medical education for primary care providers
- Provide a more comprehensive surveillance system to obtain reliable information on the numbers of people affected by arthritis
- Continue strong partnerships with members of the SC Arthritis Steering Committee and solidify partnerships with key allies, such as the SC Osteoporosis Coalition, the SC Physical Activity Coalition, the SC Nutrition Council, and the SC Mental Health Association.

II. Epidemiology and Research

A. Surveillance

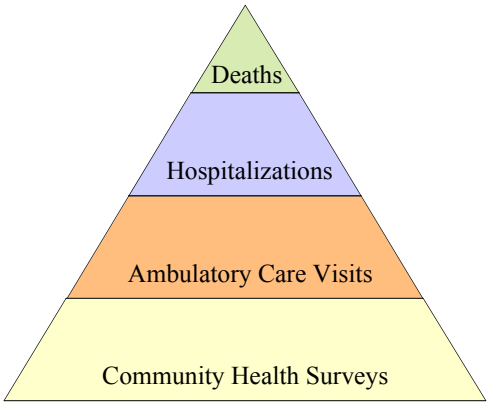
Current South Carolina arthritis surveillance efforts focus on the use of the Behavioral Risk Factor Surveillance Survey (BRFSS) to obtain state-specific prevalence data for arthritis and the impact of arthritis on quality of life and activity limitation. The BRFSS is a random digit-dialed telephone survey of adults, age 18 years and older developed by the Centers for Disease Control and Prevention. The BRFSS is designed to estimate the prevalence of behavioral risk factors and some chronic conditions at the state level. It was first administered in South Carolina in 1984 and is conducted on an on-going basis each year. It was designed to collect information about the risk factors and risk behaviors related to the major causes of morbidity and mortality in South Carolina. The South Carolina Department of Health and Environmental Control (DHEC), Bureau of Epidemiology oversees the activities of the South Carolina BRFSS.

South Carolina began administering the arthritis module of questions from the SC BRFSS in January 2000 as part of a CDC cooperative agreement, "Reducing the Burden of Arthritis and other Rheumatic Conditions." Beginning January 2001, several arthritis questions will be included in the core BRFSS questionnaire and the same questions will be used as an optional module on years when they are not in the core, thus trying to achieve continuous surveillance of arthritis both nationally and at the state level.

According to the 2000 SC BRFSS, approximately 906,003 (32%) out of 2,831,079 non-institutionalized adults in South Carolina reported having either chronic joint symptoms (CJS) or doctor-diagnosed arthritis, which is the CDC-recommended case definition for arthritis. The impact of arthritis on the health-care system has been measured using SC hospital discharge and SC emergency room data. Results from this data indicate that in South Carolina persons with arthritis and other rheumatic conditions accounted for over 9,200 hospital discharges and over 35,000 emergency room visits.

However, as illustrated in the surveillance pyramid (at right), these data may only provide information at the tip of the pyramid and do not capture the majority of patient encounters with the health care system. For example, nationally persons with arthritis and other rheumatic conditions accounted for 744,000 hospital discharges, 2 million emergency room visits, and 39 million physician office visits in 1997(ref). Therefore, additional sources of data have been obtained through partnerships and collaborations.

Surveillance Pyramid



B. Additional Data Sources

Numerous data sources have been identified for the surveillance of arthritis and other rheumatic conditions. Following the surveillance pyramid above presented at the Arthritis Regional Meeting on August 7-8, 2000 in Chicago, Illinois, a summary of available data sources are listed in Table # 5.

Table # 5 Summary of Data Sources for Arthritis Surveillance

Deaths	
**	SC Vital Records Mortality Data 1986-1998
Hospitalizations	
**	SC Hospital Discharge Data 1986-1999
Ambulatory Care Visits	
**	SC Emergency Room Data 1996-1999
#	SC Medicare Part B (PGBA) - Aggregate Data
#	SC Medicaid – Aggregate Data
#	SC State Health Insurance Plan Data – Aggregate Data
#	SC Community Health Centers
Community Health Surveys	
*	SC Behavioral Risk Factor Surveillance System (SC BRFSS) Survey – Arthritis Module
*	SC DHEC In-Home Prevention Program for Seniors

* Several data sources are currently available within the SC DHEC, Bureau of Epidemiology. The Division of Epidemiology Surveillance and Program Support oversees the activities of the SC BRFSS including data management and analysis.

** Several other data sources are available for analysis by the Division of Epidemiology Surveillance and Program Support through partnerships. The SC DHEC Division of Biostatistics maintains the Mortality Data and the SC Budget and Control Board, Office of Research and Statistics (ORS) maintains the SC Hospital Discharge Data and SC Emergency Room Data. These agencies have provided these data sources to the Division of Epidemiology Surveillance and Program Support for analysis.

Collaborations with many other agencies and organizations allow for the collection of aggregate data in the form of reports responding to specific data requests. Medicare data on arthritis from physician encounters as well as non-physician encounters including information on medical equipment and medication for arthritis used in the home are available through the Palmetto Government Benefits Administration (PGBA). Medicaid and the SC State Health Insurance Plan data are available through ORS. Additionally, SC DHEC through the Primary Care Association is working with community health centers to obtain clinic-based data.

C. Data Limitations

The SC BRFSS is the primary tool used in the surveillance of arthritis to obtain state-specific prevalence data for arthritis and the impact of arthritis on quality of life and

activity limitation. However, there are limitations of the survey, some of which are listed below.

- Prevalence rates do not represent the entire population because it excludes persons without telephones and those in institutions (e.g., nursing homes) who may be at high risk of arthritis.
- Limited participation due to time and functional capacity required to complete the survey.
- Self-reported data
- Restricted to "any type" of arthritis, not specific types
- Restricted to persons 18 years and older, no information on children with arthritis

Current data sources do not capture the majority of patient encounters with the health-care system. Data from physician encounters are needed to provide information on specific types of arthritis and information on medications and other treatments. Although some sources for these data are available through partnerships as discussed above, data centralization is critical. Without data centralization, data from a variety of sources cannot be linked because of the absence of identifiers and centralization of arthritis data. Therefore, a patient's disease progression and treatment cannot be followed.

D. Risk Factors

Certain factors are known to be associated with a greater risk of arthritis. Three of these factors are nonmodifiable: female sex, older age, and genetic predisposition. In South Carolina, approximately 37% of women and 60% of persons 65 years and older have arthritis, based on data from the 2000 SC BRFSS. Even though these factors cannot be changed, knowledge of their presence helps identify groups at higher risk for arthritis so that intervention efforts can be targeted accordingly.

Some demographic factors, such as lower levels of education and lower income, are associated with arthritis. In South Carolina, approximately 55% of persons with less than a high school education have arthritis, based on data from the 2000 SC BRFSS. Although, these risk factors are potentially modifiable, it is not clear if modifying them would indeed reduce the risk of arthritis, since the mechanisms by which they increase that risk are not yet understood.

A few clearly modifiable risk factors are also associated with increased risk of arthritis. These include obesity, joint injuries, infections, and certain occupations. A CDC study examined factors associated with the prevalence of self-reported arthritis (ref). The results of that analysis indicate that a higher risk for arthritis is associated with obesity. Persons who were obese were 1.5 (women) and 1.7 (men) times more likely to have self-reported arthritis. In South Carolina, 45% of obese persons and 40% of persons reporting no leisure time physical activity in the past month have arthritis. This is compared to 25% of normal weight persons and 29% of persons reporting some leisure time physical activity in the past month based on data from the 2000 SC BRFSS.

Although some forms of arthritis can be prevented with weight control and precautions to avoid certain occupational and sports injuries, the pain and disability accompanying all types of arthritis can be minimized through early diagnosis and appropriate management, including weight control and physical activity. According to the 2000 SC BRFSS, 31% of persons with arthritis are obese and 34% reported no leisure time physical activity in the past month. The prevalence rate of obesity and physical inactivity is higher among women and decreased with higher education levels. Obesity is

highest among black, non-Hispanics and persons ages 45-64 years. Physical inactivity is highest among Hispanics and increased with age.

Table # 6 Prevalence rate of obesity and physical inactivity by selected characteristics - SC BRFSS, 2000

Characteristic	Obesity (%)	Physical Inactivity (%)
Sex		
Female	23.5	30.4
Male	20.5	25.6
Age (years)		
18-44	19.9	23.8
45-64	27.8	29.6
≥ 65	19.2	38.9
Education (years)		
<8	28.6	64.3
9-11	30.6	46.2
12 or equivalent	25.6	32.5
13-15	18.2	21.3
16+	17.2	15.8
Race/Ethnicity		
White, non-Hispanic	18.1	24.3
Black, non-Hispanic	33.6	35.1
Hispanic	22.7	48.9
Other	23.7	30.6

E. Research

Research on arthritis and other rheumatic conditions in South Carolina is in formative stages, with the primary focus of research interest based in Clemson University in Clemson, the Medical University of South Carolina (MUSC) in Charleston, and the University of South Carolina (USC) School of Public Health Prevention and Research Center in Columbia. At the USC School of Public Health and its Prevention Center, researchers have proposed or conducted studies on fibromyalgia and post-traumatic stress syndrome; complementary and alternative medicine (described in CAM section following); arthritis, mobility, and activity limitation in seniors; and physical activity and nutrition.

At MUSC, the National Institute on Health (NIH) has provided $934,876 in research awards to South Carolina for fiscal year 2000. Dr. Gary S. Gilkerson of MUSC was provided a grant to study lupus patients and murine studies to provide insight into

immune factors promoting nitric oxide (NO) production in disease using genetically deficient mice. This study is ongoing and is scheduled to be completed March 31, 2002.

Maria Trojanowska, also of MUSC was granted funding for clinical research. The overall goal of her research is to understand the regulation of extracellular matrix (ECM) production in human fibroblasts and its deregulation in fibrotic diseases such as systematic scleroderma. This study began January 1, 1998 and is scheduled to be completed December 2001.

The National Nutraceutical Center (NNC) is a collaborative effort between Clemson University, the SC Research Authority and MUSC. The vision of the Center is to make nutraceuticals an integral part of American health care through scientific study. Its mission is to provide an environment in which academia, government and industry can partner. A number of new initiatives for 2001 have been announced. These include a raw materials certification program to assure manufactures of ingredient quality; a clinical trials program to assess product efficacy: and a drug discovery program in which new plant medicinals are being explored in tropical rainforests.

Regarding the certification program, the NNC is now working with industry, the Governor's Office and the S.C. Department of Commerce to develop a certification standard and a trade name (e.g. Carolina Gold) for medicinal plants. Through scientific studies funded by the Governor's Office and conducted by Clemson researchers, a certification program outlining new cultivation practices to ensure the highest levels of active principle are being developed. The program's intent is to grow medicinal plants under organic conditions with superior pharmacological properties. For more information, contact Dr. J. David Gangemi, Ph.D, Executive Director, National Nutraceutical Center, 124 Long Hall, Clemson University, Clemson, S.C. 29634. Telephone 864-656-6463; fax 864-656-1127.

F. Surveillance and Research: Where We Want to Go

Foundational surveillance will be continued through administering the SC BRFSS to obtain state-specific prevalence data for arthritis and the impact of arthritis on the quality of life and activity limitation. This includes information on:

- population–based information
- prevalence of arthritis
    - demographic information
- other arthritis specific information
- impact of arthritis on a person's physical and mental health including
    - physical health – physical illness and injury
    - mental health – stress, depression, problems with emotions
    - pain
    - activity limitation
    - general health
- risk factor information
    - obesity
    - physical activity

In addition, DHEC arthritis surveillance will include collaborations with multiple agencies to combine data on arthritis to build a comprehensive database. The database will include, but not be limited to costs, children with arthritis, specific types of arthritis, and medications and other treatments.

Collaborations for surveillance will also stimulate interest in research to understand more of the etiology of the various arthritis and related conditions and their prevention, control, treatment and eventual cure. In addition, the SC Arthritis Steering Committee and the future coalition will seek ways to stimulate research interest by showing the great need for this activity in South Carolina. Steering Committee members will play a key role in making the case for the importance of increasing research and in recommending which kinds would be most valuable in our state.

III. Communication Education and Prevention

While the size of the South Carolina population affected by arthritis is difficult to measure, we do know arthritis affects people of all ages, including children. According to the Arthritis Foundation, arthritis affects one in every seven people and one in every three families has someone with arthritis. Although the population in South Carolina is growing, including a substantial number of in-migrating retirees, public awareness of arthritis in the state is very limited. The importance of prevention, early diagnosis and appropriate management of the diseases is not being effectively conveyed to many people with arthritis, resulting in needless suffering.

Except for the Arthritis Foundation's programs, no public awareness campaigns have been offered in recent years to promote education and awareness about the effects of arthritis on patients, their families, work and social relationships. Because a lack of knowledge prevails, many are not aware of medications and treatments available that could improve their quality of life. Improved education and availability of information about arthritis can facilitate healthy behaviors, improve access to early treatment and reduce fears about effective treatments. The object of this chapter is to propose ways to educate the public about arthritis. Strategies for educating health care professionals and policy makers will also be addressed.

A. Communication Education and Prevention: Where We Want to Go

Several prevention strategies for arthritis are similar to risk-factor reduction strategies for other chronic conditions. Local health departments already have public information programs in place directed toward increasing physical activity, promoting a healthy diet, and reducing obesity. These programs can be modified to incorporate arthritis-specific messages. In addition, health departments have the opportunity to design programs directed at reducing arthritis disability through prevention messages. Strategies include:

- Facilitate partnerships between public health agencies and private providers to provide appropriate arthritis education across the natural disease spectrum, from diagnosis to disability management in all types of care settings.
- Incorporate self-help classes into communities to aid in education of those with arthritis. This could be done through local health agencies, Arthritis Foundation and its support groups or through hospitals and other medical practice groups.
- Set up a trained volunteer-based hotline for answering simple arthritis questions and for resource referral.
- Develop and disseminate arthritis management education programs for health professionals. Make presentations at medical associations and other health care associations in South Carolina.

Other specific strategies are addressed below, broken out by agency or audiences in terms of the DHEC Arthritis Program, the public, policy makers, PWA's, families, and caregivers.

B. DHEC Arthritis Program Communication Strategies

The DHEC Arthritis Program has begun to develop ways to communicate the "arthritis message" statewide. Partnerships developed with organizations serving people with arthritis will help get the word out to the general public and the professional community. The DHEC Arthritis Program's communication goals are to improve arthritis education by focusing on improved management and prevention of arthritis, and to increase arthritis screenings. To achieve these goals, two audiences are being targeted: the general public and physicians. Brochures, cards, and flyers are being developed for each of these target audiences.

Brochures for the general public will be written in Spanish and in English. These materials will be distributed to the general public through personal contacts and by placing them at health departments and waiting rooms of physicians.

Through cover letters, phone calls, office visits, and follow-up communications, we will develop working relationships with general practice physicians and rheumatologists. A packet of information is being developed consisting of brochures, flyers, and contact information. These materials will increase awareness of health department services and encourage physicians to utilize and communicate health department arthritis services to their patients.

To reinforce personal contacts with target audiences, staff will communicate health department services through other channels. Press releases, print ads, and public service announcements will be used to disseminate arthritis related information such as self-help courses. Arthritis Awareness Month in May will be heavily promoted and tied in to Women's Health Month in May. By developing partnerships the DHEC Arthritis Program plans to coordinate an event, such as the Arthritis Walk, to increase awareness of arthritis and arthritis treatment.

C. Communication Strategies For The Public

Arthritis touches people in all walks of life and of all ages. Prevailing myths and misinformation such as "arthritis is an inevitable consequence of aging "and "there is nothing you can do about it" dominate current arthritis information. Millions of dollars are spent to promote pain-relieving products for the "minor aches and pains of arthritis." Accurate messages about arthritis must be disseminated throughout the community to counteract misleading myths and perceptions.

Ways to accomplish this include:

- Developing messages and communication campaigns that reach people with undiagnosed arthritis to prompt people to seek early diagnosis and appropriate management.
- Adding arthritis injury prevention information to sports education program curriculums to reach high-risk populations.
- Developing messages to educate the public about the link between arthritis and weight management, physical activity and nutrition.
- Incorporating arthritis prevention messages in health-education and healthy lifestyle programs in public schools and work places.

D. Communication Strategies for Policy Makers

Before effective arthritis-related policies can be developed, policy makers need to be made aware that arthritis is an important public health issue. Policy makers must be educated about the prevalence of arthritis in South Carolina, the psychological, social and economic impact of arthritis in the state. Messages to legislators should include information on:

- What the issues are so that effective policies can be made to meet the needs of people with arthritis residing in South Carolina.
- Current successful arthritis programs to garner support for their continuation or expansion.
- The potential role of third party providers in covering any intervention proven to be effective and cost efficient.

Organized efforts to educate legislators are needed such as sponsoring an advocacy day, testimonials in committee hearings, or providing an "Arthritis Legislative Breakfast" before the beginning of the legislative session in January.

E. Communication Strategies For People with Arthritis, Families, Other Caregivers, and Health Care Providers

Strategies For People With Arthritis and their Families

State and local communication campaigns can be created to motivate people with arthritis symptoms to seek early diagnosis and appropriate management. People with arthritis can become active self-managers and successfully reduce their disability and threats to quality of life that arthritis can pose. However, many people with arthritis are either unaware of self-management strategies or find self-management behaviors difficult to adopt. Potential strategies to address these concerns include:

- Designing a comprehensive educational and motivational arthritis campaign to increase awareness of appropriate self-management and help people with arthritis overcome their personal barriers to adopting self-management behaviors.
- Developing arthritis protocols that address early diagnosis, medical treatment, and management of arthritis to ensure quality care.
- Updating existing educational materials and adapting for use by large minority groups such as the Hispanic population in South Carolina. Educational materials could be developed for delivery through interactive television, the Internet, and CD ROM to benefit persons who have access to emerging technology.
- Distributing current information that encourages people with arthritis to avoid using unproven arthritis remedies. People with arthritis have the right to make informed decisions about the use of treatments to supplement medical care. Information on "unproven remedies" needs to be widely disseminated.
- Monitoring and restricting the untruthful promotion of unproven remedies on the World Wide Web and other promotion avenues. Identification of factors contributing to the use of unproven, harmful remedies and development of messages to counteract those factors may be of benefit.

Strategies For Health Care Providers

For purposes of this discussion, health care providers are defined as all clinical, community, and public health professionals who potentially affect the health and well being of people with or at risk of arthritis. Included in this group are rheumatologists,

podiatrists, orthotists, pedorthists, nurses, chiropractors, pharmacists, health educators, fitness professionals, social workers, counselors and others.

Because most people with arthritis initially see a primary care provider in their quest for a diagnosis, primary care physicians are the first line of defense for the early diagnosis and appropriate management of arthritis. Primary care training programs may vary in the amount of attention given to rheumatology training, even though arthritis is one of the most common conditions seen by primary care physicians. Increased training and continuing medical education on arthritis would address this discrepancy. Knowledge, attitudes, and practices of primary care practitioners and other physicians can be improved through undergraduate and graduate education, continuing medical education, and in-service education.

Listed below are strategies for meeting primary care provider training:

- Provide arthritis education by partnering with third party providers, and partnering with organizations such as the Arthritis Foundation to provide increased expertise in medical education.
- Heighten physician awareness by using testimonies of influential opinion leaders.
- Recruit arthritis-related organizations, programs and foundations to advocate for core rheumatology training in all primary care training programs.
- Test the use of alternative teaching mechanisms such as interactive media, relevant internet training sites, or distance learning (that also provide continuing education credits) for busy physicians to determine most efficient/effective training methods.
- Develop a training module that emphasizes the importance of early diagnosis, appropriate management and the value of self-management and other non-pharmacological treatment.
- Make presentations at Medical Association and Health Care Associations in South Carolina.
- Encourage professional education on arthritis when offering training for health care workers, such as the Arthritis Foundation videoconference training that offers continuing education credits for health care workers.
- Develop relationships with the SC Rheumatologists Association and the SC Association of Arthritis Health Care Providers to plan peer education programs.
- Develop partnerships between public health agencies and private health providers to provide appropriate arthritis education across the natural disease spectrum, from pre-diagnosis through disability management, and in all types of care settings.

IV. Programs and Resources For Care Of Arthritis

The purpose of this chapter is to outline resources identified in South Carolina for arthritis care, self-management, educational resources, infrastructure and partnership development. These attempts to list resources are not all inclusive. There are numerous

organizations, agencies, and programs that serve people with arthritis in South Carolina. Please send any information that you have about arthritis resources to DHEC Arthritis Prevention and Control Program, Home Health, SC DHEC, PO Box 101106, Columbia, SC 29211.

A. Health Care Listings:

Free Health Clinics

There are 19 Free Medical Clinics in South Carolina serving the medically underserved population (indigent local residents who are without Medicaid, Medicare, or health insurance). Services offered vary from clinic to clinic. Most commonly offered services are general medical. Some clinics offer dental, pharmacy, and medicine assistance and other support services. See the Yellow Pages under *Clinics* for listings.

S.C. Primary Health Care
Community Health Centers
2211 Alpine Road Ext.
Columbia, SC 29223
(803) 788-2778

There are 18 federally funded community health centers distributed throughout the state. These health centers provide services based on "sliding fee scale" and can assist eligible, low-income people with their health care needs.

Rheumatologists
For listings contact:
Arthritis Foundation
1-800-883-8806

Fibromyalgia Network health care referrals (listings are up-dated every 2 months)
1-800-853-2929

Lupus Foundation of America, Inc.
For health care listings, contact:
SC Chapter
Ms. Karen Hankins Reddings
P.O. 1427
Easley, SC 29641
(864)-269-2887

B. Community Organizations/Resources

a. Support Groups Listings:

Arthritis Support Groups:

Arthritis Foundation support groups
For listings contact:
The Arthritis Foundation Of The Carolinas
Suite 217
5019 Nations Crossing
Charlotte, NC 28217

1-800-833-8806

Conway Hospital
Wellness & Fitness Center
2369 Cypress Circle
Conway, SC 29526
(843) 347-1515

Carolinas Hospital System
805 Pamplico Hwy.
Florence, SC 29505
(843) 674-5000
Arthritis and related conditions support group
(843-393-7256)

St. Francis Hospital
Bernardine Center-3rd Fl.
One St. Francis Dr.
Greenville, SC 29601
(864) 255-1653

Fibromyalgia Support Groups:

Fibromyalgia Network support group
For listings contact:
1-800-853-2929

Wellspring Resource Center
1825 St. Julian Place
Columbia, SC 2960-6481
(803) 765-9355

St. Francis Hospital
One Saint Francis Drive
Greenville, SC 29601
(864) 255-1653

Cornerstone Presbyterian Church
Fibromyaglia and chronic fatigue support group
5637 Bush River Road
Columbia, SC
Ginger Thompson
(803) 781-2983

Matin Chiropractic Group
3525 Bush River Road
Columbia, SC
Nancy Jones
(803) 772-2784

McLeod Medical Center
555 E. Cheves
Florence, SC 29506
(843) 777-2000
Fibromyalgia support group and periodic arthritis screenings

Spartanburg Regional Healthcare System
Rehabilitation Dept.
101 E. Wood St.
Spartanburg, SC 29303
(864) 560-6173
Fibromyalgia support group

Lupus Support Groups:

Piedmont HealthCare System
222 Herlong St.
Rockhill, SC 29732-1158
(803) 329-1234

Lupus Foundation, SC Chapter
For referral to lupus support groups contact:
Ms. Karen Hankins Redding
(864) 269-2887

b. Aquatics

Arthritis Foundation (AF) Aquatic Programs
For listings contact:
The Arthritis Foundation Of The Carolinas
1-800-833-8600.

Aiken Regional Medical Centers
302 University Parkway
Aiken, SC 29802
(803) 641-5000
Water aerobics provided by a certified fitness instructor

Capitol Senior Center At Maxcy Gregg Park
1650 Park Circle
Columbia, SC 29202
(803) 779-1971
Aquatics provided by a certified aquatics instructor for person's age 50 or older

Health South Rehab Hospital Florence
900 Cheves St.
Florence, SC 29506
(843) 679-9000
Aquatic exercises by certified physical therapist

Life Center of Greenville Hospitals Systems
875 West Farris Rd.
Greenville, SC 29605
A. F. certified aquatics instructor
Contact: Beth Rush
(864) 455-4231

Eastside YMCA
1250 Taylors Rd.
Taylors, SC 29687
Contact: Rebecca Barnes
(864) 292-2790

YMCA
Fitness Center
111 E. Carolina Avenue
Hartsville, SC 29550
(843) 383-4547
Offers water aerobics class provided by certified water aerobics instructor (water temp.is 83 degrees)

Clarendon Memorial Hospital
10 Hospital Street
Manning, SC 29012
(803) 435-8463
Aquatic program is taught by an A.F. certified instructor

Aquatics cont'd.

McLeod Fitness Center
2437 Willwood Dr.
Florence, SC 29506
(843) 777-3000
AF certified instructor for aquatics

YMCA Fitness Center
1700 Rutherford Road
Florence, SC 29505
(843) 665-1234
AF certified instructor for aquatics

Mary Black Memorial Hospital
1700 Skylyn Dr.
Spartanburg, SC 29307
(864) 573-3000
Aquatics therapy, water temp is 89 degrees.

c. PACE (People With Arthritis Can Exercise):

Arthritis Foundation PACE Programs
Contact: Arthritis Foundation Of The Carolinas

1-800-883-8806

Arthritis Foundation PACE Program
TRMC Health Plex
1345 Grove Park, N.E.
Orangeburg, SC 29115
(803) 534-0780
People With Arthritis Can Exercise

Fitness Forum
120 E. Elm Street
Florence, SC 29508
Contact: Courtney Bond
(843) 661-3800
Arthritis Foundation exercise program designed specifically for the water.

d. Specialized Land Exercise Programs:

Capital Senior Center At Maxcy Gregg Park
1650 Park Circle
Columbia, SC 2901
(803) 779-1971
Land-based exercise provided, by a certified senior fitness instructor/Arthritis Foundation certified, for ages 50 or older

Fitness Center
1700 Rutherford Road
Florence, SC 29205
(843) 665-1234
Fitness instruction for individuals with arthritis on exercise equipment

Georgetown Memorial Hospital
Outpatient Therapy Center
219 Church Street
Georgetown, SC 2944
(843) 545-5188
Therapeutic Exercises & Modalities, Self-help Devices, Individual and Group therapy, Functional Skills Training, Pain Management, Joint Protection, Energy Conservation, Stress Management and Patient/Family Education

Carolina Pines Regional Medical Center
Rehab. Dept.
1304 W. Bobo Newsom Hwy
Hartsville, SC 29550
(803) 339-4120
Outpatient services-pain management and arthritis exercise programs, by physician referral

Specialized Land Exercise cont'd.

Conway Hospital Wellness & Fitness Center
2369 Cypress Dr.
Conway, SC 29526
Contact: Debra Plitt
(843) 347-1515
Land-based exercise program for fibromyalgia

YMCA

Spartanburg Regional Healthcare System
Rehab. Dept.
101 E. Wood St.
Spartanburg, SC 29303
(864) 560-6173
Outpatient exercise class for (people w/ fibromyalgia) offered by physical therapists and massage therapy

Listed below are resources available (not arthritis specific):

Marlboro Park Hospital
Physical Therapy Dept.
1138 Cheraw Hwy.
Bennettsville, SC 29512
(843) 479-2881
Joint protection education (out-patient service), physician referral needed

Roper Hospital
316 Calhoun St.
Charleston, SC 29401
Contact: Matt Severance
(843) 724-2000
Periodic seminars on hip and knee pain

Laurens County Health Care System
923 East Main Street
Laurens, SC 29360
(864) 682-7730
Health Touch Rehab. Services-massage therapy, sports treatment

Resources Available cont'd.

Marion County Medical Center
2829 East Hwy.
Mullins, SC 29574
(843) 431-2000

d. Therapies

Cardiac Rehab. Dept.
Exercise equipment available (bikes, treadmills etc.) not limited to cardiac pts., physician permission may be required

Georgetown Memorial Hospital
HealthPoint
12965 Ocean Drive Hwy.
Pawley's Island, SC 29585
(843) 237-5956
Aquatic program

Cannon Memorial Hospital
Wellness and Fitness Center
123 W.G. Acker Drive
Pickens, SC 29671-0188
(864) 878-4791, ext. 291
A nationally certified exercise program, (Body Recall) for seniors (mostly), stretching and (a little) strength training is offered by a Body Recall certified instructor

Oconee Memorial Hospital
298 Memorial Dr.
Seneca, SC 29672
Contact: Ellie Taylor
Wellness Center (fitness program) * plan to offer arthritis self-care
(864) 885-7654

Wallace Thompson Hospital
Rehab. Dept.
720-A S. Duncan by Pass
Union, SC 29379
864-429-3003
Exercise machines for small monthly fee, physician referral required

Nutritionists-
Home Health Services at your local health department or contact the state office at (803) 898-0760.

Physical Therapists and Occupational Therapists-
Contact DHEC Home Health Services at your local health department (for homebound persons).

Medical University of South Carolina
Bone and Joint Center
2125 Charlie Hall Blvd.
Charleston, SC 29414
(843) 573-1550

(Listed above are public providers, see the yellow pages for private therapy providers).

e. Programs For Medicine Assistance:

Patient Assistance Programs:
The Medicine Program-seeks to aid those who have exhausted all other sources for help with medication and helps people to apply for enrollment in one or more of the many patient assistance programs now available. This process is accomplished with the cooperation of the applicant's physician. Your local Area Agency On Aging can help you apply.

Indigent Drug Programs-located at some of the local Free Medical Clinics; ask about an indigent drug program.

Commun-I-Care- **(**1-800-763-0059)-for people without any type of health insurance, Medicaid, Medicare or veteran benefits. To be eligible for drug support for certain medications and 1 free physician visit to assess need, a person must be employed or have recently lost their job.

f. DHEC Programs:
In-Home Prevention For Seniors (IHPS**)**
South Carolina Arthritis Prevention and Control Program (SCAPCP)

In-Home Prevention Services For Seniors

IHPSS is a program that promotes healthy aging by helping seniors remain active and functional in their homes. The program serves persons who are 65 years or older, who are independent in activities of daily living (ADLs). The program provides accessible preventive services to both urban and rural populations. Participants receive a comprehensive in-home assessment conducted by a registered nurse. The client, nurse and others collaborate to develop an individualized health promotion plan. Primarily client goals are focused on preventing injuries, chronic illness and their complications.

IHPSS uses a local approach to solving local problems. Volunteers from the local area assist program staff to recruit seniors, provide services to clients, and promote the program throughout the community to recruit seniors, provide program services to clients, and promote the program throughout the community.

Start-up programs have begun in 10 counties, Anderson, Oconee, Beaufort, Jasper, Hampton, Aiken, Barnwell, Allendale, Williamsburg and Georgetown. Additional funding is needed to expand the program to serve seniors in the remainder of the state.

Additional funding has been requested to expand the program to serve seniors in four additional health districts for 2001. Unfortunately, due to a large budget shortfall for the State of South Carolina, all agencies except the SC Department of Education were asked to take up to a 15% budget cut from their agency budget. The impact of the projected budget cut taken at DHEC will be severe and will likely reduce the IHPSS program.

g. DHEC Arthritis Prevention and Control Program (The Arthritis Program)

Medical social workers and nursing staff are being trained to become "arthritis specialists", and will offer Arthritis Foundation Self-Help Courses in local health departments statewide. Arthritis specific individual and group services will be offered at the local health departments.

Social Worker Services provides assistance with stress management, strengthening of social support systems, and also provide linkages to community services and resources. Nutritional Counseling is offered by a licensed dietitian for persons with weight difficulties or inadequate dietary practices. Physical Therapy and Occupational Therapy are available (through the Home Health Services Program) for persons who are homebound. Nursing Services are available to provide education on how to manage disease and to provide skilled care if a client becomes homebound.

Health department staff was trained in October 2000 by the Arthritis Foundation on the Fibromyalgia Self-Help Course. The staff is preparing to provide these classes in the local health departments beginning in April 2001.

Additional funding is needed to assist with the cost of self-help course materials, provide scholarships to self-help classes, and fund both individual and group services for persons with arthritis who are uninsured and underinsured. DHEC is exploring possible funding sources such as additional grant monies, linking with pharmaceutical companies to fund arthritis specialized services and other community resources.

An arthritis resource guide is available for each local area and can be expanded into an arthritis information and resource directory for South Carolina.

h. Arthritis Foundation Services/Programs

The Arthritis Foundation offers the Fibromyalgia and Arthritis Self-Help Courses and PACE (People With Arthritis Can Exercise) training for leaders in North Carolina and South Carolina. Trained leaders can then become certified to provide the training to the general public. (At DHEC, AF trainers are being recruited to provide training to district social work and nursing staff.)

Other Programs offered by the Arthritis Foundation are:

Arthritis Foundation Youth Ambassador Program is a program where youth and young adults involved with the program represent themselves, other persons with Juvenile Arthritis and the Arthritis Foundation (AF) within the community. Some of the youth

attend special events, programs and speaking engagements to share their experiences with Juvenile Arthritis.

Arthritis Foundation Discoveries Program is a relatively new program available for speaking engagements. Arthritis Foundation staff and physicians who have been trained are available to provide the program to the community.

Taking Control of Arthritis Program is another relatively new turnkey Program available through the AF for community workshops. The Arthritis Foundation Programs and Services Director is the only person trained in SC and NC to provide this workshop at this time.

The Arthritis Foundation lists 4 AF arthritis support groups, (1 in each of the following areas, Charleston, Darlington, Greenville, Spartanburg).

There are 25 AF Aquatic Exercise Program locations listed by the Arthritis Foundation in SC. Aquatic classes are offered in 11 locations in the upper part of the state, 3 in the low country region, 8 in the Pee Dee region, and 3 in the Midlands region of the state.

Listed are 6 locations offering the Arthritis Foundation Self-Help Course. Two locations in Charleston offer the AF Arthritis Self Help Course. The Arthritis Self Help Course is also offered in Greenville, Darlington and Walterboro. The Arthritis, Fibromyalgia and Lupus Self Help Courses are offered in Florence.

i. SC Vocational Rehabilitation Programs and Services

1410 Boston Ave.
West Columbia, SC 29170
(803) 896-6500
Contact your local Vocational Rehabilitation office to learn more about services.

SC Vocational Rehabilitation's **Center For Comprehensive Programs** enhances employability and includes an Evaluation Center, Pain Management Program (where clients can learn to successfully cope with orthopedic pain), Muscular Development Program featuring physical therapy, aquatic therapy facilities, Rehabilitation Technology Program (helps people with physical disabilities overcome physical barriers), a Barrier-Free Model Home displaying residential adaptations for persons with disabilities and Computer Training Program.

j. Area Agencies On Aging

South Carolina has 10 Area Agencies On Aging/Councils Of Governments (COG). Offered are programs for home care (light household cleaning, daily chores, shopping, meal preparation), transportation (for eligible persons), senior companions, (trained

volunteers), meal delivery (Meals On Wheels), sitter services, respite services, Wellness Centers (nutrition, exercise programs, outings) and other programs/services.

Private Providers of homecare services, sitter services, etc.- contact your local area agency on aging for listings.

k. Complementary Care-
Office Of Complementary Medicine, MUSC
30 B Street
Suite 2100
Charleston, SC 29425
(804) 792-1270

Massage Therapy

A credentialed masseuse/masseur in SC is licensed by the SC Department Of Labor, Licensing and Regulations.

Acupuncture

South Carolina State Board Of Medical Examiners
(803) 896-4500
Acupuncturists must have permission to practice under a licensed MD or dentist.

Chiropractic

A credentialed chiropractor in SC is licensed by the SC Chiropractic Board Of Examiners.

Herbal Therapy
Consult with your physician about herbs, vitamin supplements/drug interactions.

l. Miscellaneous Resources:

Insurance- I – CARE-Insurance Counseling Assistance and Referral for elders, contact your area agency on aging.

Assistive/Adaptive Devices-equipment loans / donate equipment, contact:
local churches, your local area agency on aging (Medi-Loan Services)

Financial Assistance-Social Security Administration
1-800-772-1213 –administers the Security Income Program, determines eligibility under Medicare program.

m. Counseling/Advocacy

Wellsprings Resource Center
P. O. Box 6481
Columbia, SC 292609-6481

(803) 765-9355 for referrals

Local health departments for individual and group counseling, and self-help courses

C. Publications/Resources

The National Arthritis and Musculoskeletal and Skin Diseases
Information Clearinghouse (NAMSIC)
Box AMS
9000 Rockville Pike
Bethesda, Maryland 20892
(301) 496-8188
NAMSIC is a national resource center for information about professional, patient, and public education materials; community demonstration programs; and Federal programs related to rheumatic, musculoskeletal, and skin diseases. The Clearinghouse maintains a bibliographic database of educational materials.

2000-2001 Senior Services Directory
designed by Central Midlands Council of Governments
236-Stoneridge Drive
Columbia, SC 29210
(803) 376-5390
This directory assists you in identifying support services needed to help people maintain independence in the later years. Listed are Midlands Area Aging service providers of congregate meals, Meals On Wheels, social and leisure programs, home makers services, consumer information contacts, legal service and other services provided.

Wellspring Annual Directory of Complementary and Integrative
Health Resources
(803) 765-9355
This annual directory offers information on health-building options suggested reading, websites, national organizations, and local practitioners**.**

Lupus News
1300 Piccard Drive
Suite 220
Rockville, MD 20850-4303

Arthritis Agenda
A periodic electronic newsletter is produced by:
Office of Public Policy & Advocacy
Arthritis Foundation
4455 Connecticut Ave.

NW, Suite 305
Washington, D.C. 20008
(202) 537-5471

For brochures:
Arthritis Foundation Of the Carolinas-1-800-883-8806
Lupus Foundation of America, Inc.-1-877-895-8787
Fibromyalgia Network-1-800-853-2929

D. Partnerships and Collaborations

The SC Arthritis Program has established an infrastructure within DHEC with the Volunteer Program, Public Information Program, In Home Prevention Services for Seniors Program, Chronic Disease Epidemiology Branch, Migrant Health and other programs to support and assist the Program's prevention and control efforts. The Arthritis Steering Committee was developed and convened for the first time in June 2000. Experts from around the state were recruited to guide and direct the DHEC Arthritis Prevention and Control Program. Committee members will be key players in marketing the state plan and spin off fact sheets and will form a future coalition with an expanded membership. The following is a listing of South Carolina Arthritis Control Program Partnerships:

Arthritis Foundation Inc.
Carolinas Chapter
Suite 217
5019 Nations Crossing
Charlotte, NC 28217

South Carolina Vocational Rehabilitation
1410 Boston Avenue
West Columbia, SC 29170

Department Of Health and Human Services
P.O. Box 8206
Columbia, SC 29202

Affiliated Family Services
2229 Bull Street
Columbia, SC 29201

Mitchell C. Feinman, M.D., F.A.C.P.
1737 Villagepark Drive
Orangeburg, SC 29118

Central Midlands Council Of Governments

Columbia Fibromyalgia Support Group
Wellsprings Resource Center
1825 St. Julian Place
PO Box 6481
Columbia, SC 2960-6481

Conway Hospital
Wellness and Fitness Center
Conway, SC 29526

Hand and Upper Extremity
Rehabilitation Department
St. Francis Health System
1 St. Francis Drive
Greenville, SC 29601

Department of Human Nutrition
Winthrop University
302 Life Sciences
Rock Hill, SC 29733

Prevention and Research Center
School of Public Health
University of South Carolina
Columbia, SC 29208

236 Stoneridge Drive
Columbia, SC 29210

Spartanburg Arthritis Support Group
630 Riveroak Road
Inman, SC 29439

YMCA of Greater Spartanburg
266 South Pine Street
Spartanburg, SC 29302

Blue Cross and Blue Shield
I-20 @ Alpine Road
Mail Code AF-325
Columbia, SC 29219

MUSC Department
171 Ashley Avenue
Charleston, SC 29425

Hand Therapy Center
1120 Grove Road, Suite A
Greenville, SC 29605

Greenville Support Group
8 Georgetown Circle
Taylors, SC 29687

Columbia Arthritis Center
1711 St. Julian Place
Columbia, SC 29201

Medical University of South Carolina
Office of Complementary Medicine
30 B Street
Charleston SC 29425

Department of Rehabilitation Sciences
MUSC Physical Therapy Department
Rutledge Towers
135 Rutledge Towers
Charleston, SC 29425

Parish Nurse Program
Providence Hospital
3524 Forest Drive
Columbia, SC 29204

Institute of Public Affairs
University of South Carolina
1122 Plaza Bldg.
Columbia, SC 29208

Hawthorne Pharmacy
1500 Taylor Street
Columbia, SC 29201

Lupus Foundation, Inc
SC Chapter
PO Box 1427
Easley, SC 29640

Future efforts will be made to develop partnerships with other agencies/organizations and may include the SC Department Of Transportation, SC Department Of Mental Health, SC Department of Disabilities and Special Needs and others serving persons with arthritis.

V. Access To Services And Care

A. Medical Care

The Mature Adults Count (1998) reports that having a physician or medical facility nearby to provide for basic and appropriate levels of health care will become critical as the population increases. Currently, parts of all 46 of South Carolina's counties are recognized by the federal government as either Health Professional Shortage Areas or Medically Underserved Areas. With the increase in aging population, including those moving into the state, some areas will face serious shortages of certain types of medical care. The need for geriatric specialists will rise. Rural areas will be particularly hard hit, where care is now non-existent and transportation is not always available, particularly for low-income elderly. Because of low Medicare and Medicaid reimbursement rates, a number of mature adults have difficulty finding a medical home.

In "Studies Warn of Shortage Among Health Specialists" (S. Borenstein, **The State Newspaper,** December 6, 2000), major factors for the switch from too many specialists to too few specialists were identified by Ed Salsberg, director of the Center For Health Workforce Studies at the State University of New York at Albany, and Dr. Mark Kelley, Executive Vice President of the Henry Ford Health System. These factors boiled down to one major demographic change: The aging population. By 2010, the first baby boomer will reach 65, the age when health often worsens, putting the bulk of the US population more at risk for heart and lung diseases as well as cancer. The medical community decided a decade ago that America had too many specialists and not enough general physicians, so more students went into general practice. Planners expected managed health care to restrict use of specialists, but that did not happen. People demanded to go to specialists, such as cardiologists when they had heart problems, Kelley said. In a recent study, Salsburg found imminent shortages in anesthesiologists, allergists and gerontologists.

In South Carolina, there is a projected shortage of licensed physicians qualified to treat patients with arthritis. Currently in the state, 34 licensed physicians are qualified to treat patients with arthritis who also satisfy the additional criteria established by the Arthritis Foundation. Many of these rheumatologists have a waiting list of anywhere between five to eleven weeks for a new patient to be seen.

Not only is the availability of rheumatologists limited, the geographic distribution of arthritis specialists imposes another problem for people with arthritis. Fourteen arthritis specialists (on the Arthritis Foundation list) are located in Charleston county, where the prevalence of activity limitation from arthritis (SC BRFSS 1998) is low for the state. Very few of them practice in the counties where the prevalence rate is the highest. Eight rheumatologists are located in the Greenville/Spartanburg area and 4 in Richland county. (See Appendix II for map of arthritis prevalence by county).

Physician Shortages: Where We Want to Go

Strategies described to address the projected shortage of arthritis specialists and the geographical distribution problem are:

- Educate schools and universities, about the need for more arthritis specialists/rheumatologists in underserved areas of the state

- Encourage prospective students to accept federal government loans that offer the ability to pay back loans by serving in designated underserved areas.
- Publicize the need for more trained arthritis specialists on web sites used by physicians and medical students exploring specialty areas.

B. Access to Transportation

The Seniors Aging in South Carolina: A Profile and Needs Assessment (1999) developed by Senior Matters Consulting, Inc. with the Department of Government and International Studies, University Of South Carolina cited transportation as the top ten issue of concern among seniors. In today's society, more and more families are finding themselves mobile, leaving senior members living alone in a community without any family support or assistance. Often a senior's only way to get to his or her doctor appointments or buy groceries and/or prescription drugs is through the use of some form of public or private transportation system. Many seniors using the existing transportation systems stated that they must call days in advance to schedule transportation. Even calling ahead to schedule transportation often does not assure the senior will make the appointment on time or have prompt service. According to the above report, several testimonies told of seniors having to board a bus at 9:00 a.m. to get transportation to a 3:00 p.m. appointment, because that is what worked best for the service provider. After they reach their destination, often they are left waiting for hours outside grocery stores or in a doctor's waiting room for their return trip home. *The Executive Summary Report* developed by DGA Consulting Services in association with Delowe Corporation for the South Carolina Department of Highways and Public Transportation validated the transportation concerns expressed by seniors. This study focused on the needs of transportation for three specialized populations that included the elderly, disabled, and low income. The report indicated that approximately 190 different human services agencies are currently providing or purchasing transportation services for their clients. The report projected the demand for specialized transit services in the area of 24,992,742 annual trips. Service providers of transportation in South Carolina are currently providing only around 18,939,809 annual specialized passenger trips. Therefore existing services are currently meeting approximately 75.8% of the estimated demand for services, meaning that about 24.2% remain unserved (see Appendix III, SC Department of Transportation, *Mass Transportation Systems* state map). Thirty-one states, not including South Carolina, have some form of legislation/and or executive order that addresses the coordination of transportation services. Some of the states are in the process of developing a coordinated transit system for their community. The Pee Dee Rural Transit Authority and Greenville Transit Authority are just two of the agencies working hard to meet the demands for transportation. The Greenville Transit Authority coordinating effort increased the number of trips per month by 3,292 and reduced the average cost per passenger trip by $4.30.

Robert Barber (personal communication, December 5, 2000), a lobbyist for the Transportation Association of SC, noted that there is duplication of transportation services in the state and that coordination is needed to provide efficient public transportation services to South Carolinians. Strategies to address problems with the transportation system must include a statewide coordinated effort, involving the transportation stakeholders in the discussion.

Transportation: Where We Want to Go

Given the extent of this problem and the major government agencies and consumer groups who would need to be involved, preliminary strategies are only offered below:

- Use the Arthritis Steering Committee and future Arthritis Coalition to publicize the serious problem that transportation poses for Seniors and PWA's.

- Work through future Arthritis Coalition to encourage to explore potential partnerships to address transportation issues and needs in South Carolina.

C. Access to Medication

The high cost of prescription drugs to treat arthritis and rheumatoid conditions is a concern reported by people with arthritis and related rheumatic conditions. Davis Hook, a local pharmacist (personal communication, March 1, 2001) reported that, "depending on the dosage, the average cost of a "best therapy" (Cox-2 inhibitor) arthritis medication is $60.00 to $85.00 monthly. For those who have no insurance or are underinsured, the high cost of some superior prescription drugs, can place a financial burden on them and may force them to choose less expensive generic medications." According to Mr. Hook, a knowledgeable pharmacist can direct persons on ways to obtain a 90-day medication supply on maintenance prescriptions and may be able to suggest other ways to help reduce costs.

FDA approved the first Cox-2 inhibitor, Celebrex (celecoxib), in December 1998 to treat rheumatoid arthritis and osteoarthritis. Vioxx (refecoxib) became the second COX-2 inhibitor to receive approval, in May 1999, but only for the treatment of arthritis, dysmenorrhea, and the relief of acute pain in adults, such as that caused by dental surgery. Both drugs, taken orally, were found to substantially lower the risk of stomach and upper intestinal ulcers detected by endoscopy in clinical trials, compared with other NSAIDs. Additional studies are needed to determine whether Celebrex and Vioxx actually cause fewer serious stomach problems, including GI ulceration, bleeding and perforation. Until such studies are done, FDA is requiring the drugs' labeling to include the standard warning about the GI risks that are associated with NSAIDS (Lewis, 2000).

The most recently approved treatment regimen for rheumatoid arthritis is one that combines the genetically engineered biological drug Remicaide (infliximab) with the drug methotrexate. Approved in November 1998, Enbrel (etanercept) is the first biologic response modifier to receive FDA approval for patients with moderate to severe RA. Taken twice weekly by injection, Enbrel was shown to decrease pain and morning stiffness and improve joint swelling and tenderness. In June 2000, the drug's uses were expanded to include delaying structural damage (Lewis, 2000).

Arava (leflunomide) is the first oral treatment for slowing down the progression of RA. Although its effects are similar to those of methotrexate, this drug works by a different chemical mechanism, blocking an enzyme in certain lymphocytes (a type of white blood cell that is part of the immune system) and thereby retarding the progression of the disease (Lewis, 2000).

Some cost examples obtained from Web RX.com www.rxlist.com (3/13/01), are listed below:

1) The current price of thirty (30) 100 mg. capsules of Celebrex is $41.65.
2) The current price of thirty (30) 25 mg. tablets of Vioxx is $73.45.
3) The current price of thirty-six (36) 2.5 mg. tablets of Methotrexate is $23.95. Methotrexate is commonly used to treat disabling psoriasis, rheumatoid arthritis, some cancers, and other uses as determined by a doctor.

4) The current price (according to Eckerd Pharmacy on 3/21/01) of Enbrel, 25 mg. injections twice weekly for a 30-day supply is $1,140.19 and for Arava (FDA approved in September 1998) 20 mg. for a 30-day supply is $129.39.

Many medications are prescribed for the treatment of arthritis and related conditions. The above listed medications are examples only. Persons with arthritis should consult with a medical doctor to help them find the medication and treatment that works best for them.

The Arthritis Foundation publishes an updated drug guide to provide general information for use in consultation with a doctor or other health-care provider. The **Arthritis Today's Drug Guide** can be ordered by contacting the Arthritis Foundation at 1-800-207-8633.

According to Drug Manufacturer's Programs To Help Americans Obtain Their Medications: An Information Paper Prepared by the Staff Of The Special Committee on Aging, *United States Senate (1999)*, many Americans find it difficult to afford life-saving prescription drugs for their prescription medication. Some must go without food or energy in order to afford their prescription. Others simply stop taking their medication altogether when they can no longer afford it. For persons receiving Medicaid, the coverage of four prescriptions is not always enough.

Some pharmaceutical companies offer free medication to low-income families. They require a doctor's consent and proof of financial status. Insurance coverage for prescription medicines determines who is eligible to apply. A few companies even allow family incomes as high as $ 40,000 annually (offset by expenses). Copies of this publication (*Free Medication Program For Low Income People*) are available in hard copy by e-mailing the Special Committee On Aging, United States Senate at mailbox@aging.senate.gov.

Access to Medication: Where We Want to Go

Potential strategies that have been described for improving access to medication for arthritis include:

- Encouraging agencies and organizations serving persons with arthritis to develop partnerships with pharmaceutical companies to facilitate easier access to needed medications.
- Educating people about the benefits of developing good working relationships with knowledgeable local pharmacists.
- Encouraging and supporting new prescription drug discount initiatives such as SilverCard and educating persons about SilverCard. (In October 2000, the South Carolina Governor's Office announced the SilverCard prescription drug initiative. Seniors with SilverCard will receive a discount on their prescription drugs. SilverCard will benefit those seniors age 65 year and older who have no other prescription drug insurance. Qualifying seniors will be able to start using SilverCard at participating pharmacies on January 1, 2001).
- Supporting legislation recommending prescription drug pricing reform.

D. Financial

People who are not debilitated with arthritis and rheumatoid conditions may be able to continue to work with modifications. Holding on to a job means you will have a vastly improved chance of maintaining your lifestyle, your positive mental health, and your self-esteem. Whether or not you continue to work depends on how well you feel, your attitude, and your employer (Pitzele, 1986).

One approach to aid PWA's to continue functioning at home and at work is the use of universal design in equipment and building construction. Universal design is a process through which products and environments are designed so anyone can use them, regardless of age or ability. This is quite different from barrier-free or accessible design, which requires compliance with specific regulations to eliminate physical barriers for a segment of the population. Where accessible design is concerned with people with disabilities, universal design is concerned with everyone, including people with disabilities (Salmen, 1996).

Supporting research and advocacy for universal building designs may help people with arthritis continue to be productive at work. Encouraging employers to provide specific work modifications such as providing a flexible work schedule to help employees with arthritis make up any time they may have missed due to their condition may enable an employee with arthritis to continue to be productive at work.

Persons with Arthritis who are disabled and have not yet been accepted for Social Security Disability and Medicaid benefits are often not able to pay for medical services, supportive and treatment programs (medication physical therapy, nutrition education, counseling to help cope with/manage illness, community resource assistance, advocacy services, aquatics exercise, and etc.) during the lengthy wait (average of 120 days) for a decision to be made regarding their disability claim by the Social Security Administration (SSA). According to the SSA, if a person is denied benefits on an initial claim and wants to appeal this decision, the applicant must then send an application/letter to appeal within 60 days. Once the letter is received, it will take another 60 days for the appeal to be processed.

Financial Relief: Where We Want to Go

Potential strategies that have been described to provide financial relief for people with arthritis who are disabled or unable to work a full-time job are:

- Provide advocacy to assist persons with arthritis to obtain needed individual and group services, to help them navigate complex systems of care and guide them through the frequently difficult application processes in order to expedite receipt of needed services. These services are offered at the local health departments. Health department staff can be trained and services adapted to meet the unique needs of people with arthritis and arthritis related conditions and
- Educate employers about tax incentives for employing persons with disabilities so that those who can and want to work are given an opportunity to work part-time. Eligible people can then apply for and receive disability benefits.

The numbers of working poor in South Carolina are up dramatically (Robert, 2000). According to the Census Bureau (2000), 569,000 people or 14.9 percent of South

Carolina residents lived in poverty in 1997. The working poor who do not have paid sick leave and health care benefits must take unpaid leave time from work and also pay the full cost of medical treatments. Passing legislation to make health insurance fully tax deductible for people not covered by employer-subsidized plans may make health care more affordable.

E. Access To Services

There is no "one stop shop" in South Carolina serving persons with arthritis. Services are spread out and are not coordinated. The Medical University of South Carolina's Bone and Joint Center in Charleston is the area's most comprehensive group of its kind. The Bone Center specializes in the diagnosis and treatment of problems and injuries of the back, spine, pelvis, hips, knees, shoulders, elbows and neck. Complete adult and pediatric services include: Rheumatology, Complementary and Alternative Medicine, Orthopedics, Radiology, Sports Medicine, Physical and Occupational Therapy and Pain Management. Some staff at MUSC have a vision of housing and coordinating all these services under one roof. This coordinated effort would make a comprehensive array of services more accessible to people with arthritis.

Only a few Arthritis Foundation-sponsored aquatic programs are listed by the AF in the middle and lower parts of the state. The Arthritis Foundation of the Carolinas lists one Arthritis Self-Help course offered in the Upstate region of the state, two in the Pee Dee region, and three in the Low Country Region. Conway hospital (Pee Dee region) offers a modified fibromyalia self-help course. One Arthritis Foundation Fibromyalgia and Lupus Self-Help course is also offered in the Pee Dee region. Beginning in April 2000, DHEC plans to offer the Arthritis Foundation Fibromyalgia Self-Help courses statewide. The Arthritis Foundation lists four support groups in South Carolina. More information is needed from providers and consumers on the availability of these types of programs to add resource/referral lists.

Access to Services: Where We Want to Go

Strategies that have been proposed to improve service access include:

- Completing a needs assessment of arthritis services in the state.
- Continuing to coordinate training health department social workers and nurses to provide the AF Self-Help courses statewide as partnership between DHEC and the Arthritis Foundation.
- Developing a lupus self-help course sponsored by DHEC and train staff to provide the course statewide (training through the AF is no longer available on the AF Lupus Self-Help Course).
- Encouraging partners to provide arthritis land-based exercises and aquatics programs in underserved areas.
- Providing technical support to partners to start up support groups in underserved areas.
- Supporting the AF of the Carolinas proposal to allot a 15% increase in the organization's budget to expand Foundation Programs and Services.

F. Access To Information

Access to information in South Carolina is poor. There is no existing centralized clearinghouse for arthritis specific information and referral to services other than for Arthritis Foundation of the Carolina's programs and services. The Arthritis Foundation of the Carolinas serves both South Carolina and North Carolina and readily admits there exists a lack of funding for Arthritis Programs and Services in South Carolina.

Information on arthritis is not readily available in underserved areas of South Carolina. As Mildred Porter, a resident of rural Lexington County, so aptly explains in, *A Need for Knowledge* (**The Lexington Chronicle**, October 19, 2000), " I was scared. I didn't have any idea what rheumatoid arthritis really was, and I had no idea what to expect. If they (physicians) had said cancer, diabetes, stroke, pneumonia, I would have had some idea at least."

Efforts to increase the accessibility of information must take into consideration the unique characteristics of the population in the state. According to the US Department of Educational, National Adult Literacy Survey (NALS), (1993), twenty-five percent of the adult population in South Carolina is at Level 1 Literacy, the lowest literacy level. The following counties with (adult populations of at least 5,000) have the lowest literacy levels in the state: Allendale County (46%), Clarendon County (40%), Bamberg (39%), Hampton and Fairfield Counties (37%), Calhoun (35%), and Colleton and Dillon (34%) are at Level 1 Literacy.

According to the US Census Bureau (2000), the Hispanic population has increased by 15.1 % in the state between 1990 and 1999. Greenville (379, 616), Richland (320,677), Charleston (309,969), Spartanburg (226,793), Lexington (216,014), Horry (196,629), and Anderson (165,740) counties have the largest number of the Hispanic residents in South Carolina.

Access to Information: Where We Want to Go

Proposed strategies include:

- Developing and distributing culturally sensitive information on arthritis to the general population (target people of various literacy levels and write information in languages representative of the population).
- Reviewing and explaining brochures, handouts and screening information with target populations as appropriate.
- Developing an arthritis resource guide for local areas.
- Expanding the resource guide into a continuously up-dated information and referral service for persons with arthritis residing in South Carolina by using current program staff and funding a graduate assistantship position.

VI. Other Considerations for Arthritis Treatment and Care

A. Complementary and Alternative Medicine

(By Patricia Sharpe, PhD, MPH, University of South Carolina School of Public Health Prevention and Research Center)

Because osteoarthritis, rheumatoid arthritis and fibromyalgia have no cure, can involve considerable pain and disability, and exact a heavy toll on quality of life, it is not surprising that persons with these conditions would seek out a variety of complementary and alternative therapies as means for managing illness. Furthermore, commonly prescribed anti-inflammatory drugs have serious side effects for some people. In recent years, the use of complementary and alternative medicine (CAM) has gained increasing popularity among the general public and among persons with arthritis and other rheumatoid conditions.

The National Institutes of Health defines CAM in the United States as those treatments and health care practices that are not taught widely in medical schools and not generally used in hospitals. These therapies are also often called "unconventional therapies," because they are outside of mainstream Western medicine for the most part. Most often these therapies have not undergone rigorous scientific analysis, however, a growing body of research shows promise for some CAM therapies.

While it has been suggested that CAM use is driven by anti-scientific sentiment and a rejection of conventional medicine, research does not support these claims. CAM users overall tend to combine CAM with conventional medicine (Astin, 1998: Berman & Swyers, 1997), although the majority of users do not inform their doctors of their CAM use (Astin, Pelletier, Marie, & Haskell, 2000; Eisenberg, 1993, 1998). CAM users tend to be relatively affluent and well educated (Eisenberg, 1993, 1998).

Literature reviews have revealed that the most popular treatment modalities for persons with rheumatoid conditions are chiropractic, acupuncture, massage, and homeopathy; however, definitive conclusions about the prevalence of specific modalities are not possible due to differing definitions of CAM (Ernst,1998: Ramos-Remus, Gutierrez & Davis, 1999). The use of dietary modifications, herbal and vitamin/mineral supplementation, an array of home/folk remedies, relaxation/meditation and other mind-body approaches, exercise, spirituality/prayer, and many other approaches have also been reported.

Of those respondents reporting arthritis as a principal condition in Eisenberg's (1993) national survey sample, only 18% reported CAM use, with 7% having consulted a CAM provider in the previous year. In a South Carolina random sample survey of CAM use of 1500 persons, less than 5% of persons reporting arthritis had used CAM in the previous year (Oldendick et al., 2000) in rheumatology practice settings. Whether these differences reflect differing definitions of CAM, differing modes of data collection, or real differences between clinic-based samples and general population samples in CAM use is not clear.

Dr. Ann Coker and colleagues at the University of South Carolina have collected descriptive data on complementary and alternative medicine (CAM) use in South Carolina. Dr. Coker was team co-leader with Dr. Robert Oldendick of the University Of South Carolina's Complementary and Alternative Medicine working group in 1999. The

team conducted two studies using South Carolina based surveys of CAM use by 1584 survey respondents from the general population in South Carolina and CAM use and CAM referral patterns by 327 South Carolina based physicians. The University of South Carolina Survey Research Laboratory conducted these surveys.

In the cross sectional study of adults, 44% had used a CAM therapy in the past year. CAM use was associated with increasing age and higher income. More than 60% of respondents perceived CAM as "very effective", and 89% would recommend CAM to others. The most commonly reported lifetime and past-year uses of CAM therapies were the "personal therapies" such as home remedies, herbs, and vitamins; second to personal therapies were massage and relaxation therapies. Chiropractic topped the list for persons with musculoskeletal and neurologic conditions. Fifty-seven percent of respondents had not informed their physicians of their CAM use. In a state with a large rural and minority population such as South Carolina, this survey suggests that CAM use overall is comparable to that found in national telephone surveys. Of the 1584 respondents, 314 (20.3%) respondents reported having arthritis (Oldendick et al., 2000).

Data from the USC physician survey of 327 physicians are currently being analyzed. Preliminary analyses reveal that, among physicians whose patients express an interest in CAM, 56.6% encourage the use of relaxation techniques, 21.1% encourage chiropractic, 47.1% encourage massage therapy, 15.6% encourage visual imagery, 15.3% encourage spiritual healing, 21.7% encourage lifestyle diets, 17.1% encourage use of herbs, 36.1% encourage vitamin therapy, 62.4% encourage self-help groups, 21.1% encourage home remedies, 71.3% encourage prayer and 87.5% encourage exercise. The CAM that physicians most often reported making referrals for was exercise (73.7%), self-help groups (60.2%), prayer (40.7%), and massage (35.8%).

Currently, research on CAM efficacy is in the early stages. Depending on the type of therapy, research on efficacy for arthritis ranges from non-existent to promising. Definitive statements about efficacy specific to arthritis and related conditions are not possible. Based on the available peer reviewed literature, it is safe to say that some CAM therapies show promise, in general for pain management; stress/anxiety/depression reduction; sleep improvement; and general quality of life, and that these benefits may accrue to persons with arthritis within a coordinated, integrative approach involving cooperation among physicians, CAM practitioners, and persons with arthritis.

Most CAM therapies are not covered by health insurance in South Carolina. Blue Cross and Blue Shield of South Carolina, the largest health insurance provider in the state, provides their subscribers with a list of some licensed CAM practitioners who have agreed to offer a discount to Blue Cross and Blue Shield subscribers in return for being listed in this directory. Most consumers are typically unable to pay for CAM therapies out of pocket. With growing consumer demand for access to CAM services, consumers and some CAM practitioners have begun to advocate for insurance coverage for CAM services, and some states have passed legislation requiring such coverage. While insurance companies have begun to investigate the feasibility of covering some CAM services, this remains a controversial topic among CAM practitioners, physicians, and the health industry.

CAM: Where We Want to Go

Given the widespread use of CAM among persons with arthritis, the SC Arthritis Program envisions a neutral, facilitative role in providing a forum for discussion among CAM providers, persons with arthritis, insurance representatives, and mainstream rheumatology and general practice medical professionals concerning the potential benefits and cautions of incorporating CAM into arthritis care, as well as reimbursement issues. Additionally, the Arthritis Steering Committee would like to promote dissemination of accurate, up to date information for persons with arthritis and health care professionals concerning CAM and research results on CAM efficacy for arthritis care.

Note to Reader: References for Dr. Sharpe's article are integrated in state plan reference section at end of this document.

B. Nutrition and Arthritis

(By Patricia Wolman, EdD, RD, Department of Human Nutrition, Winthrop University, Rock Hill, SC)

Up until 20 years ago, arthritis sufferers were told that there was no nutrition treatment other than the maintenance of ideal body weight and a varied diet. Overweight persons with osteoarthritis were told to lose weight and underweight individuals with rheumatoid arthritis were told to gain weight. All were instructed to eat a balanced diet, but no hope of change in their disease status was offered based on dietary intake. In 1984, the Arthritis Foundation acknowledged that there might be some nutrition therapies that merit further investigation (Panush, 1984).

Allergies

As early as 1914 food allergies were associated with arthritis. Sensitivity to food resulting in joint pain and swelling is often found in conjunction with such other allergic disorders as hay fever, asthma, and rhinitis. Case studies and limited clinical trials offer evidence that some clients may be sensitive to specific foods causing rheumatoid arthritis symptoms (Kroker, Stroud, & Marshall, 1984; Panush & Webster, 1985). When Panush et al. (1983) studied 26 individuals with rheumatoid arthritis on a 10-week, controlled, double-blind study of a no meat, no dairy products, no additives diet promoted by Dong and Banks (1975), no differences between the control and experimental groups were observed in clinical, laboratory, or immunologic measures. However, at least four of the subjects reported improvement in morning stiffness, swollen joints, grip strength, and other objective measures and remained on the diet after the completion of the study.

Allergy-prone individuals, especially those with food allergies, sensitivities, or intolerances, may benefit from exclusion of specific foods from their diets. Foods that cause arthritis symptoms may also produce nasal and gastrointestinal symptoms. The offending foods appear to be specific to individuals (Collier, 1989); however, milk products, corn and cereals have been implicated (Buchanan, Preston, Brooks & Buchanan, 1991). Fasting, elimination diets, and careful food intake records are required

to determine which foods appear to cause symptoms. Subjectivity and observer-bias are problems since the client or caretaker must delineate which specific foods are related to symptoms. Darlington, Ramsey and Mansfield (1986) pointed out that any improvement observed may be due to incidental weight loss or placebo effect. In spite of these problems, elimination diets are safe and noninvasive and should be considered for cooperative, allergy-prone clients.

Fasting

Liquid diets or 7 – 10 day fasts have been used as a prelude to an elimination diet. In many cases, fasting has resulted in relief of symptoms of rheumatoid arthritis. Short term fasting under supervision may beneficial for some clients, but should always be used with caution (Kjeldsen-Kragh et al., 1991; Kjeldsen-Kragh, 1999; Palmblad, Hafstrom & Ringertz, 1991).

Vegetarian Diets

Several variations on vegetarian diets have been recommended for arthritis therapy over the past several decades. In 1983, Skoldstam measured the effectiveness of a 4-month vegan diet with no sugar, corn flour, salt, alcoholic beverages, coffee, or tea. The 20 subjects with rheumatoid arthritis showed improvement in ability to perform activities of daily living and reported less pain. However, such objective measures as grip strength, index of joint tenderness, number of joints involved, inflammation, erythrocyte sedimentation rate, concentration of C-reactive protein and C3 did not change in 60% of the patients.

In 1991, Kjeldsen-Kragh et al. reported that a vegetarian diet, following a 7 to 10 day fasting period, was effective in improving tender joints, pain, morning stiffness, and grip strength in 27 patients with rheumatoid arthritis. Objective measures of white blood cell count and C-reactive protein also showed improvement. The vegetarian diet was individually adjusted and did not include gluten; milk products were added to the diet after three and one-half months. After one year on the vegetarian diet, the group continued to show improvement (Kjeldsen-Kragh et al., 1991). Nenonen, Helve, Ruama and Hanninen (1998) studied an uncooked vegan diet with high lactobaccilli content in individuals with rheumatoid arthritis. Subjects in the experimental group reported statistically significant improvement in subjective measures of pain, swelling, and stiffness.

Whether or not individuals have positive improvements in symptoms due to weight loss on vegetarian diets is not clear. However, if clients experience less pain and can be more independent, vegetarian diets can be a harmless and generally beneficial regimen. Those following a vegan diet need to understand protein complementarity and may need to supplement vitamins B12 and D as well as calcium and zinc.

Fatty Acids

The use of polyunsaturated oils, especially fish oil supplements (omega-3 fatty acids), have been investigated in the treatment of inflammation and pain associated with several forms of arthritis. Polyunsaturated fatty acids are precursors of prostaglandin, leukotriences, and thromboxanes. Series 1 prostaglandins are synthesized from linoleic acid; series 2 prostaglandins are synthesized from arachidonic acid and series 3 prostaglandins from linolenic acid (Gropper, 2000). In 1983, Ziff suggested that a change in the fatty acid composition of the diet might be helpful in decreasing the inflammation associated with arthritis.

Early studies by Kremer et al. (1987) indicated that the ingestion of fish oil concentrate resulted in statistically significant delayed onset of fatigue and fewer tender joints in 33 patients with rheumatoid arthritis. Such measures as morning stiffness, grip strength, personal assessment of pain, physicians' assessment of pain, walking time, and joint swelling showed improvement, but the results were not statistically significant (Kremer, Jubiz & Michalek, 1987). Later work by Kremer and colleagues (1995) indicated that subjects with rheumatoid arthritis taking fish oil supplements (130 mg/kg/day of omega-3 fatty acids) had statistically significant reduction in joint tenderness, morning stiffness, and patients' and physicians' assessment of pain. A meta-analysis of the effects of fish oil by Fortin et al. (1995) determined that dietary fish oil supplementation significantly reduced morning stiffness and number of tender joints in rheumatoid arthritis. Olive oil may also be associated with improvement in clinical and immunological factors in rheumatoid arthritis (Kremer et al., 1990).

While intake of omega-3 fatty acids improves symptoms of patients with rheumatoid arthritis, lifetime intake of fish oil capsules is an unrealistic goal (Mantzioris et al., 2000). Instead, encouraging greater intakes of such naturally high omega-3 fatty acid foods such as mackerel, salmon, bluefish, and sardines is harmless and may have beneficial effects (Wolman, 1990). In addition, foods not naturally high in omega-3 fatty acids, could be enriched or fortified with omega-3 fatty acid to increase their therapeutic effect (Mantzioris et al. 2000).

Supplements of Gamma-linolenic acid (GLA) found in evening primrose oil, borage oil and black current oil may have a role in the treatment of rheumatoid arthritis (Fan & Chapkin, 1998). Evening primrose oil and borage oil may suppress inflammation in rheumatoid arthritis (Belch & Hill, 2000).

Vitamins, Minerals and Other Dietary Supplements

Vitamin and mineral supplementation in excess of up to 3000 times the Recommended Dietary Allowances (RDA) has been suggested for the amelioration or cure of arthritis in the popular press (Wolman, 1987). Low intake and low serum levels of vitamin D may be related to osteoarthritis of the knee (McAlindon et al., 1996). In its role as a free-radical scavenger, vitamin E supplementation may play a role in relieving pain in osteoarthritis (Packer, 1991). Zinc, copper, selenium, boron may have roles in the prevention and treatment of arthritis, but more clinical trials are needed.

Other supplements covered under the Dietary Supplement Health and Education Act of 1994 include glucosamine and chondrotin sulfate and such other substances botanicals and phytochemicals. Glucosamine and chondroitin sulfate, used for years in

veterinary medicine, has been touted in the popular press for treatment of osteoarthritis. The National Institutes of Health (NIH) is supporting multicenter, placebo-controlled, clinical trials on ingestion of glucosamine alone, chondroitin sulfate alone, and glucosamine and chondroitin sulfate together; results will be published in 2004 (Hochberg et al, 2000).

Licorice root and devil's claw root have been used in traditional medicine as anti-inflammatory agents in the treatment of osteoarthritis. Flaxseed has been suggested as helpful in the treatment of rheumatoid arthritis; willow bark may give symptomatic relief for rheumatic and arthritic conditions (Blumenthal, Goldberg & Brinckmann, 2000).

Maintenance of Normal Weight

The mainstay of nutrition therapy for arthritis remains the achievement and maintenance of ideal body weight. Individuals with osteoporosis may experience relief from pain after weight loss. Individuals with rheumatoid arthritis may need special food preparation and eating utensils to maintain adequate energy intake.

Food Preparation Skills

Nutrition treatment of clients with various forms of arthritis centers on relieving symptoms and minimizing side effects of treatment. Simple activities of daily living can become extremely painful and have devastating effects on nutritional status. Efforts should be made to maintain as much independence as possible. The use of a stool to sit on in the kitchen while preparing meals, the availability of utensils, use of blenders, food processors, electric can openers, and light-weight pots and pans may help a client continue to function as the major family food preparer. Suction cups on the bottom of stainless steel bowls, rubber aids for jar opening and proper counter height can make food preparation safer and less painful. If meal preparation becomes too difficult, meals on wheels or homemaker services may be required to ensure adequate nutrition intake (Wolman, 1990).

Note to Reader: References for Dr. Wolman's article are integrated in state plan reference section.

VIII. Goals and Objectives: How Do We Get There?

This section prioritizes goals and objectives for the SC Arthritis Program to achieve over the next five years to reduce the burden of arthritis in the state, reduce disability and pain due to arthritis and other rheumatic conditions and to empower South Carolinians affected by arthritis to achieve optimal health status and enhanced quality of life. Objectives are given in order of priority for implementation.

South Carolina Arthritis Prevention and Control Program Five-Year Plan, 2001-2005

Objective 1. Conduct comprehensive needs assessment to identify current resources, services, and gaps by September 15, 2003.

1.1 Identify personnel (i.e. Steering Committee members and staff) to oversee needs assessment by December 15, 2001.

a) Explore contracting with professionals to conduct needs assessment
b) Identify internal resources to conduct needs assessment if contractual not possible

1.2 Conduct 1st stage needs assessment by July 15, 2002.

a) Conduct a complete lit review
b) Research health providers and available programs
c) Identify target consumers
d) Identify potential partners

1.3 Conduct 2nd stage needs assessment by July 15, 2003.

a) Adapt previously used survey to South Carolina's needs or design new surveys (intercept, interview, or mail survey to be determined)
b) Develop/conduct focus groups with consumers to help identify service issues and message development for public education

1.4 Complete/Interpret results of needs assessment by December 15, 2003.

a) Use results to determine what kind/where services needed to fill gaps
b) Use results to determine where SCAPC can make an impact and where it cannot
c) Guide the steps for carrying out Arthritis State Plan and modify as needed through process evaluation

Measures of Success: A copy of the SC Arthritis Needs Assessment will be submitted. Results of research will be available, including published report of results of survey or focus group activity, with copies of survey instrument(s). Conduct process evaluation at particular stages of development.

Objective 2. Continue arthritis surveillance and expand means to measure burden of arthritis on people of South Carolina.

2.1 Continue the use of the Behavioral Risk Factor Surveillance Survey (BRFSS) to obtain state-specific prevalence data for arthritis and the impact of arthritis on quality of life and activity limitation (by September 30, 2005).

a) Continue to administer the core BRFSS, arthritis, and quality of life modules.
    1. The 2001 interviews began January 2001.
    2. The 2002 questions will be released in August 2001.
    3. Interviews will begin in January 2002.
b) Continue to analyze data from the core BRFSS, arthritis, and quality of life modules.
    1. Interim analyses will be performed on unweighted data as it comes available.
    2. Analysis on weighted data will be performed as it comes available. Weighted data should be available in Spring 2002.
c) Continue to develop the application of these data by providing user-friendly materials and reports.
    1. Provide arthritis surveillance data to the steering committee as they implement the state plan and a coalition develops.
    2. Use the data to promote education and awareness within the SC DHEC as well as other health care professionals, organizations, and the public through fact sheets, publications, and presentations.

2.2 Continue to expand and analyze data from other sources.

a) Continue to obtain other sources of data on arthritis from other state agencies and private organizations.
b) Collaborate with multiple agencies to link/combine data on arthritis to build a comprehensive database.

Measures of Success: Data analysis and progress reports from SC BRFSS, fact sheets, presentations and other publications, linked database or MOA reflecting collaboration among multiple agencies.

Objective 3. Develop and expand services to People With Arthritis (PWA's).

3.1 By November 15, 2002 train health department staff to develop expertise in working with persons with arthritis.

a) Schedule training programs for key public health professionals throughout the state in order to increase knowledge and skill in working with PWA's
b) Coordinate training with the Arthritis Foundation
c) Develop training for a modified lupus self-help course
d) Meet with district staff to help identify people with arthritis and to facilitate implementation of services

Measures of Success: The number of staff trained will be captured (currently 13 staff are trained). The number of trainings provided will be captured (one training has been provided for the Fibromyalgia self-help course). The type of training offered will be recorded.

3.2 By January 30, 2002, track individual and group services offered through DHEC Home Health and Long Term Care.

a) Develop a method to track services through the Home Health and Long Term Care computer system.
b) Produce reports on services offered across the state.

Measures of Success: Longitudinal data for arthritis services to individuals and groups will be captured. The number of persons served and type of services provided will be recorded.

3.3 By January 2003 increase the number of arthritis support groups in SC.

a) Identify underserved areas.
b) Coordinate with the Arthritis Foundation to provide technical support to consumers and sponsors who express interest in starting up arthritis support groups in underserved areas.

Measures of Success: The number of contacts with consumers and sponsors will be captured. The number of meetings with support groups will be documented. The number of new groups established will be reported.

3.4 By May 30, 2002 find new ways to strengthen social support for caregivers/families of PWA's.

a) Health department staff will be trained on "Caring for the Caregiver."
b) An objective tool to measure the degree of stress will be made available to staff.
c) Provide individual and group services to support caregivers.
d) Match caregivers with "Caregiver Buddy" for support.
e) Public information/education materials will be developed to increase awareness of caregiver needs.

Measures Of Success: Number of trainings will be captured. Caregiver services provided through the local Health Departments will be summarized. Number of materials disseminated will be estimated. Public information activities will be summarized.

3.5 By September 15, 2002 increase the number of arthritis specific land-based exercise programs available to people with arthritis regardless of ability to pay.

a) Partner with the Area Agencies on Aging to provide arthritis-specific exercise programs.
b) Seek other partner opportunities to expand arthritis-specific exercise programs.

Measures of Success: The number of new arthritis specific land-based exercise programs started will be captured.

3.6 By May 30, 2002 increase the use of volunteers in promoting arthritis awareness in communities.

a) Volunteers will be recruited to promote arthritis awareness.
b) Volunteers will be trained on arthritis and ways to increase community awareness.

Measures of Success: The number of volunteers recruited. The number of community contacts will be captured. The number individual services provided by volunteers will be reported.

3.7 By September 30, 2001 develop relationships with local physicians and other health care providers to make them aware of health department services and other programs that would benefit persons with arthritis and their families.

a) Health department staff will educate local physicians about services offered through the health department that would benefit persons with arthritis and their families.
b) Brochures about individual and group arthritis services have been prepared and will be made available in the local areas.
c) On-going relationships with key physicians will be established and referral processes developed.

Measures of Success: Health departments will track the number of physicians and health care providers they contact and the number of informal and formal partnerships that are developed. Health districts will report on the number of referrals that result from these contacts.

3.8 By January 30, 2004 assistance will be developed to improve choices for employment.

a) Professional health department staff will advocate for clients who want to work.
b) Staff will make referrals to and coordinate with SC Vocational Rehabilitation.
c) Efforts will be made to establish a contact at the SSA to facilitate processing of disability claims for disabled clients as appropriate.
d) Health department "arthritis specialists" will be trained about work modifications, assistive devices and employer tax credits that apply to employing persons with disabilities.
e) Health Department staff will be trained on employment options and strategies, work modifications, assistive devices, and employer tax credits for persons with disabilities.

Measures of Success: The number of staff trained will be captured. Contacts with SSA to establish liaison.Number of meetings with Vocational Rehabilitation to coordinate services.

3.9 By September 30, 2005 develop a state-based strategy to address systems change for people with arthritis and improve accessibility for persons with arthritis.

a) Task Force/Coalition will advocate for use of Universal Design Process in buildings and work accommodations to assist people with arthritis.
b) Task Force/Coalition will advocate for medication pricing reform.
c) Task Force/Coalition will advocate for a statewide coordinated, accessible transportation system.

Measures of Success: Task Force/Coalition will document advocacy efforts.

Objective 4. Develop multi-faceted public education and awareness campaign about arthritis by September 30, 2005.

4.1 By March 15, 2003, develop marketing plan using most effective vehicles for communicating information and messages.

a) Use market research conducted during needs assessment to develop messages, vehicles, identified populations
b) Target various audiences as indicated by needs assessment, potentially including consumers, professional health care providers, consumers, family members, policy makers
c) Create fact sheets and brochures, including information on programs, services, arthritis conditions, myth busters, and vital aging.
d) Explore use of radio and TV public affairs programs, radio spots, and billboards as mass communication vehicles
e) Use statewide news releases for hard news

4.2 By September 30, 2005, hold major events to build PR and awareness.

a) Develop arthritis symposiums in targeted regions
b) Develop publicity around events to recruit participants and build news coverage

Measures of Success: Copies of materials developed, copies of workshop or symposium programs, documentation of public education campaign; i.e. sample radio PSA's will be submitted.

Objective 5. By September 30, 2004 create information systems to improve access to arthritis services.

5.1 Create Arthritis Information and Referral System.

a) Train admin. Staff or recruit GA through USC SPH or SSW to run system
b) Identify phone number in HH&LTC to use as information line
c) Develop/Print Arthritis Resource Guide to use as reference for phone line and to distribute to partners/consumers
d) Develop/manage Arthritis Web Page on DHEC Web Site

5.2 Support/create opportunities for professional networking among arthritis partners.

a) Continue linkage with Arthritis Foundation network
b) Support/Sponsor workshops, support groups
c) Develop system for steering committee/coalition information exchange
d) Sponsor seminars or conferences for educational purposes and networking

Measures of Success: Staff will track the number of contacts, people served, and number of referrals that result from contacts. Publication of reference guide, posting of web site, and announcements of events with programs made available. Attendance at events will be tracked and any follow up resulting from attendance.

Objective 6. Develop a statewide coalition by September 30, 2002.

6.1 By October 1, 2001, collaborate with SC Osteoporosis Coalition to establish an Arthritis Task Force as special project of Osteoporosis Coalition.

a) Use Osteoporosis Coalition's stability to provide foundation for Task Force start-up
b) Expand Arthritis Steering Committee and partnership list to recruit members
c) Merge Arthritis Steering Committee into Arthritis Task Force
d) Spin off Task Force within two years to become independent arthritis coalition

6.2 By April 30, 2002, initiate steps to create SC Arthritis Coalition to work in partnership with DHEC, the Arthritis Foundation of Carolinas, the SC Osteoporosis Coalition, and other partners to develop prevention, education, treatment and care services for PWA's.

a) Hire coalition executive director for newly formed Arthritis Coalition
b) Create coalition infrastructure (Board, Executive Committee, subcommittees) to write by-laws, develop projects, provide education/advocacy, facilitate meeting service needs
c) Convene regular Board meetings to determine direction of coalition
d) Hold bi-annual or annual meetings for educational/informational/and networking purposes and to conduct business of coalition
e) Develop resources to sustain coalition's work

Measures of Success: Minutes of meetings, progress reports, completion of steps from task force to coalition, attendance/participation, numbers of members, numbers of activities, projects, events held and evaluation of their effectiveness in meeting their goals.

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